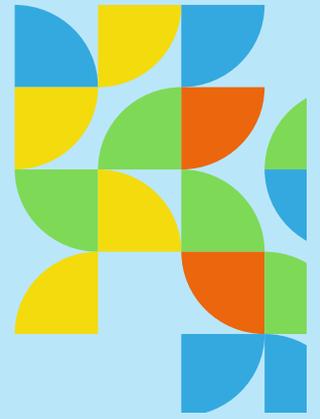


LIVING WELL WITH DEMENTIA IN SOUTH TIPPERARY:



Ten Years of Service Implementation and Sustainability into the Future

Dr. Maria Pierce and Jeremy Golden
2023



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Foreword

I am moved beyond measure to read this elegant and insightful appraisal of the Living Well with Dementia service in South Tipperary.

In 2012 when we started on this journey, with seven hundred thousand euro of funding from Genio, we wanted to change the world.

We wanted to transform the life experience of people with dementia and their families in South Tipperary.

We wanted to increase public awareness, dispel myths, reduce stigma and to encourage people to come forward earlier for diagnosis and treatment.

We knew that for most people a diagnosis of dementia was like a death sentence and we wanted to transform that perception with information and support.

But most of all we wanted to provide high quality, flexible, person-centred care to allow people to stay living at home for as long as was possible.

And now, eleven years later, just look what you have done! You have developed and sustained this service and it is now a national beacon of innovation and excellence. You have showcased how the aims of the National Dementia Strategy can be delivered putting the person with dementia and their family at the centre of everything you do.

Now more than ever, as the population with dementia trebles and as exciting new treatments are within reach, this service needs to be secured, funded and developed. This study provides powerful recommendations on just how this can be achieved.

‘Whatever you can do, or think you can, begin it.
Boldness has genius power and magic in it’.

Goethe

Dr Caitriona Crowe

Consultant in Old Age Psychiatry, St James’s Hospital, Dublin.

Lead of the ‘Five Steps to Living Well with Dementia in South Tipperary’ project, 2012 - 2015

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List of Abbreviations

ANP	Advanced Nurse Practitioner
ASI	Alzheimer Society of Ireland
AT	Assistive Technology
DNS	Dementia Nurse Specialist
DSW	Dementia Support Worker
FCI	Family Carers Ireland
GP	General Practitioner
GPS	Global Positioning System
HSE	Health Service Executive
MTL	Memory Technology Library
MTRR	Memory Technology Resource Room
NDO	National Dementia Office
OT	Occupational Therapist
PHN	Public Health Nurse
POLL	Psychiatry of Later Life
STEP	South Tipperary Enablement Programme for Older People
STUH	South Tipperary University Hospital
WTE	Whole time equivalent

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Executive Summary

Introduction

Living Well with Dementia in South Tipperary¹ provides services to people with dementia and their families living in the South Tipperary area. Originating in the 5 Steps to Living Well with Dementia in South Tipperary established in 2012, it has three main aims:

- (1) to provide a single point of contact for dementia in South Tipperary;
- (2) to support people with dementia to live full, enriched, and happy lives at home within their communities for as long as possible; and
- (3) to improve the quality of life for people with dementia by providing individualised, high quality, flexible support.

Living Well with Dementia comprises four main components – Dementia Nurse Specialist,² Senior Occupational Therapist (OT),³ Dementia Support Worker (DSW) service and Memory Technology Library (MTL). Since 2015, Living Well with Dementia has been funded by the HSE and facilitated by Family Carers Ireland (FCI) through a Section 39 grant aid agreement. The purpose of this study was to provide evidence to help inform future development and sustainability of Living Well with Dementia and to incorporate the views and perspectives of people with dementia and their family carers. The aims of the study were to:

- Succinctly describe the evolution of the Living Well with Dementia Service in South Tipperary over the years from 2012 to 2022
- Provide an overview of the supports that the service is currently providing to include an outline of the role and contribution it is making to implementing the National Dementia Strategy and an assessment of how well the service aligns with the HSE's emerging Dementia Model of Care
- Outline the role and contribution that the service makes to the lives of people with dementia and their family carers using the service, including from the perspectives of people with dementia and their family carers
- Provide an overview of how the service currently operates and where it is currently at with respect to existing resources, skills, and alliances, including an assessment of strengths and weaknesses, and its positioning within the national, regional, and local dementia ecosystem
- Identify opportunities for change within the environment in which the service operates and identify any constraints external to the service which are found to be limiting opportunities for change

¹ For brevity, Living Well with Dementia in South Tipperary will be referred to in the remainder of this report as Living Well with Dementia.

² For the remainder of the Executive Summary, the term nurse is used to refer to the Dementia Nurse Specialist at Living Well with Dementia.

³ For the remainder of the Executive Summary, the term OT is used to refer to the Senior Occupational Therapist at Living Well with Dementia.

The sustainability of the service has taken on greater significance since the study commenced, following a decision by FCI in January 2023 not to pursue a new Section 39 grant aid agreement with the HSE. This will effectively bring its role in managing Living Well with Dementia to an end in December 2023. A decision has been taken by the HSE in mid-2023 to bring the OT and MTL components of Living Well with Dementia within its remit. However, a new host organisation is now needed to take over from FCI and facilitate the nurse and DSW service components. Staff in Living Well with Dementia have been given responsibility for finding a new host organisation and at the time of writing are in discussions with a potential host organisation.

Study methodology

This study was a mixed-methods study conducted between September 2022 and February 2023. Qualitative methods were used to explore the experiences and views of a total of 47 study participants. Two focus groups were held with staff (n=8) at Living Well with Dementia in South Tipperary. Individual interviews were held with people with dementia (n=8) and family carers (n=16). Individual interviews were also held with a range of health professionals working in other services in South Tipperary (n=9) and senior management in HSE and FCI (n=6). The study included a review of service activity and expenditure data and an analysis of evaluation forms completed by people with dementia and family carers.

Evolution of Living Well with Dementia in South Tipperary

This study identified three distinct phases in the evolution of Living Well with Dementia in South Tipperary:

- *First phase (2012-2015)*: This commenced when 5 Steps to Living Well with Dementia project in 2012 was created with funded from the HSE & Genio Dementia programme. During this phase, the project demonstrated flexible, personalised supports for people with dementia. Evidence of the value of the project, its benefits for people with dementia and their family carers, and potential cost savings were provided by a series of research reports. In recognition of the project's important contribution to the dementia care landscape in South Tipperary, the HSE agreed to sustain the valuable resources and supports when the project phase came to an end in 2015.
- *Second phase (2015-2019)*: Commencement of this phase towards the end of 2015 was marked by renaming the project to Living Well with Dementia in South Tipperary. The facilitation of Living Well with Dementia by FCI under a Section 39 grant aid agreement commenced in October 2015. This was a period of embedding the service in local infrastructure. It was a time of ongoing improvement of the supports offered including development of group memory rehabilitation, psycho-education and peer support programmes. Funding from the HSE, and close working between the HSE Local Manager for Older Person's Services, the FCI Local Branch Manager and senior staff in Living Well with Dementia enabled its success. This phase was also marked by expert contribution to national programmes and resources and clinical leadership of the HSE's Memory Technology Resource Rooms programme.
- *Third phase (2020-2022)*: This has been a turbulent phase for Living Well with Dementia, with the onset of the Covid-19 pandemic in February 2020. Despite the upheaval it caused, Living Well with Dementia continued to deliver most of its services and supports, whilst at the same time protecting service users and staff against Covid-19. Unlike many other services, it achieved this balance without any additional funding. The upheaval

experienced as a result of the pandemic was exacerbated by HSE management change and FCI restructuring. These are explored in more detail in this study.

Overview of Living Well with Dementia in South Tipperary

Living Well with Dementia is located on the grounds of South Tipperary University Hospital in Clonmel. The report provides an overview of Living Well with Dementia and what makes the service distinct. These include its four main components (i.e. Dementia Nurse Specialist, OT; DSW service, and MTL) and how they fit together under the umbrella of Living Well with Dementia; the interdisciplinary nature of the service; the wide range of practical, personalised, post-diagnostic, psychosocial supports and interventions provided; and contribution to national policy and programme development and implementation. Data presented on trends in referrals, service use and funding show the increasing demand and use of supports provided by Living Well with Dementia, without any increase in funding since 2015.

Strengths of Living Well with Dementia in South Tipperary

A large number of strengths were identified by people with dementia, family carers, staff, health professionals and other stakeholders participating in interviews and focus groups for this study (Table A1). Living Well with Dementia was seen to be a unique and progressive service, which addresses a gap in dementia care services. It was regarded as a valuable addition to the dementia care landscape in South Tipperary. Living Well with Dementia was highly valued by different stakeholders for promoting the personhood of people with dementia, a key principle underpinning the Irish National Dementia Strategy. A major strength of Living Well with Dementia identified was its highly qualified, experienced specialist nurse and OT and the roles they play in assessment and care planning post-diagnosis, offering specialist information, advice, support and strategies to help people with dementia live independently and engage in daily and meaningful activities as well as to family carers. Living Well with Dementia was highly valued for the range of practical, post-diagnostic, psychosocial supports for people with dementia and their family carers and tailoring these to service users' assessed needs. The ongoing support offered to family carers who find themselves in very challenging circumstances was highlighted. The educational work and role Living Well with Dementia staff play in changing the narrative around dementia and reducing stigma was also highlighted. Participants stressed that rather than duplicating or replacing other services, Living Well with Dementia played a complementary role. Health professionals working in other services locally stressed the importance of Living Well with Dementia as a resource for them and pointed out that it freed up resources in their services and provided people with dementia with more appropriate support than they could offer. Many participants including people with dementia would like to see the model of care extended to other areas of the country.

Being inclusive of all people with dementia irrespective of age, type or severity of dementia, living circumstances or complexity of need was seen as a strength, as was its dual purpose in supporting both the person with dementia and the family carer. The range of psychosocial supports offered by Living Well with Dementia was identified as a strength. Both the DSW service and MTL were identified as vital components of Living Well with Dementia and participants spoke at length about the added value of these services. While Living Well with Dementia was seen as a distinct but complementary service, participants stressed how well

integrated it was across a number of levels, exemplified by the multidisciplinary nature of the service, its strong linkages and close working with health professionals in other services, referral pathways developed, integration with primary and community care services as well as secondary and acute services and input into long-stay residential care, as well as the links forged between local, regional and national levels. Participants identified a wide range of benefits for people with dementia, family carers and health professionals arising from Living Well with Dementia. HSE support and funding to Living Well with Dementia from the HSE was acknowledged as vital and a major strength. Participants stressed that there was a strong value case for this, because of the wellbeing gains and potential cost savings arising from a relatively low investment by the HSE. The value case was made stronger when the role that Living Well with Dementia plays in implementing national policy and the contribution that its staff make to the national policy and programmes such as the Memory Technology Resource Rooms.

Challenges facing Living Well with Dementia in South Tipperary

Seven main challenges facing Living Well with Dementia were identified by study participants (Table A2). The most immediate of these are managerial changes within the HSE and restructuring within FCI. Within the HSE, the local manager is new to the area and less familiar with Living Well with Dementia in South Tipperary. In this context, this research will provide valuable information on how the service operates, outline the benefits it has for people with dementia, family carers and health professionals in the dementia care landscape in South Tipperary and show the value case for its existence. Restructuring within FCI led to a move from Living Well with Dementia being locally to centrally managed, which coincided with an increased focus on the costs and risk management, and the implementation of changes to bring the DSW service into close alignment with FCI home respite service. Managerial change in both organisations led to a less hand-on approach with much fewer meetings. Ultimately, FCI took a decision in January 2023 not to renew the Section 39 grant aid agreement, effectively ending its role in facilitating Living Well with Dementia at the end of 2023.

A key challenge facing Living Well with Dementia identified by participants was increasing demand. The overall trend in referrals to Living Well with Dementia have been upward, which is anticipated to increase further in the coming years. Increased demand was attributed to increasing numbers of people with dementia due to population ageing, more people seeking help with memory problems as awareness and understanding of dementia among the public grows and dementia becomes perceived as less stigmatizing; more people receiving a formal diagnosis of dementia than in the past; and move towards diagnosing people with dementia at an earlier stage in the disease progression than had been the case. Given the increasing demand, and reliance of health professionals in other services on Living Well with Dementia, its existence will become increasingly important in the future.

Alongside the most immediate issue of finding a new host organisation for Living Well with Dementia, two further key challenges were identified. These are the staffing levels in Living Well with Dementia and issues in relation to the building in which it is located. The current staffing levels are considered to be inadequate for Living Well with Dementia to effectively meet the demand for its services. Following FCI's decision to cease its role in managing Living Well with Dementia, there is a strong case for appointing a service manager for Living

Well with Dementia. There is also a strong case for appointing a part-time clerical officer to provide administrative support to the nurse and OT in relation to managing referrals and appointments for nurse-led and OT-led services, assisting with administrative tasks associated with care assessment and planning, the DSW service and delivery of group programmes. The appointment of a service manager and administrative support would free up valuable time of the nurse and OT and enable them to concentrate on core aspects of their respective roles.

The location of Living Well with Dementia on the grounds of South Tipperary University Hospital (STUH) is considered to be well placed. However, there are issues with the building. The staff working in the service are faced with uncertainty as the building is not guaranteed to Living Well with Dementia and the service is under constant threat of losing the building at short notice. This issue needs to be urgently resolved. A permanent location for Living Well with Dementia needs to be found. Potentially, Living Well with Dementia could remain in its current location under an agreement negotiated with STUH. Such an agreement would need to address upkeep and maintenance issues in the building. There may be benefits in the longer-term from co-location of the Living Well with Dementia with the memory clinic.

Staff recruitment and retention is an ongoing challenge, particularly in relation to DSWs, and attrition has been exacerbated by the restructuring within FCI. DSWs were identified by senior staff in Living Well with Dementia, people with dementia and family carers, and health professionals in other services as a major asset of Living Well with Dementia. Their commitment to providing personalised support to persons with dementia, building relationships and enabling them to participate in the community was strongly evident. Any new funding mechanisms for allocating resources or arrangements for hosting Living Well with Dementia must take account of the DSW service. There is a likelihood that at some time in the future the nurse and OT may retire or move on to another position, leaving these roles vacant. Participants highlighted the need for succession planning within Living Well with Dementia, as well as a strategy for recruitment and retention.

The geography of South Tipperary, which covers a large area, has many towns and rural, mountainous and remote areas, is a challenge for Living Well with Dementia as it is for many other services in South Tipperary. Concern was expressed about the needs of people with dementia living at a distance from Clonmel and in remote areas of South Tipperary. A particular challenge is recruiting DSWs from across South Tipperary to match need and reduce travelling distances. This participants believed could be better managed locally, with knowledge of the geography of South Tipperary. The appointment of a service manager and administrative support would greatly help with this issue.

Threats facing Living Well with Dementia

The biggest threat to Living Well with Dementia has been FCI's decision to cease managing the service at the end of 2023. While the OT and MTL are to come under the HSE's remit, there is still the urgent matter of securing a host organisation for the nurse and DSW service. Staff in Living Well with Dementia have been given responsibility for finding a new host organisation and at the time of writing are in discussions with a potential host organisation. Another serious threat facing Living Well with Dementia is uncertainty regarding the building,

and urgent action is needed to negotiate with South Tipperary University Hospital and secure a longer-term tenancy agreement.

Opportunities for Living Well with Dementia in South Tipperary

Despite these challenges and threats, a number of opportunities were identified by participants. The recognition of Living Well with Dementia by the HSE and the invaluable support from the HSE, which has been ongoing since 2012, were identified as a major opportunity for Living Well with Dementia. Living Well with Dementia is a valuable asset for the HSE, because of its contribution to the implementation of the Irish National Dementia Strategy, in particular the priority action area 'Integrated Services, Supports and Care for People with Dementia and their Carers', but also in relation to the priority actions of 'Better Awareness and Understanding' and 'Training and Education'. The health professionals in Living Well with Dementia have collaborated and developed strong working relationships with the National Dementia Office (NDO). These could be revitalised with recent appointments of a new Programme Manager and Clinical Lead and harnessed to help put Living Well with Dementia on a firmer footing during its next phase of its development. The HSE's Model of Dementia Care in Ireland, launched by the Department of Health in June 2023, could provide a potential opportunity for Living Well with Dementia, as it is so closely aligned with the Model. It embodies its principles, places an emphasis on immediate care planning post-diagnosis, and plays an important role in providing post-diagnostic supports across the model's five strands. Living Well with Dementia provides an excellent working example of the Model. As funding comes on stream for the development of additional Memory Assessment and Support Services, this could potentially provide an opportunity for putting Living Well with Dementia on a firmer footing over the long-term. This study shows that Living Well with Dementia is highly valued and there is a high level of support for Living Well with Dementia locally. It may be an opportune time to bring supporters together into an alliance to work with the HSE towards finding ways of putting Living Well with Dementia on a firmer footing. In the past, the Dementia Consortium worked well as an instrument for driving change, and could be re-established and revitalised with new members to do this again. However, given the difficulties in sustaining a Dementia Consortium over a longer period, this would be for a set purpose and a set period of time.

Conclusions

This study has described the evolution of Living Well with Dementia and identified three distinct phases of development. Living Well with Dementia provides supports to people with dementia and their family carers through four main components, the DNS, OT, DSW service and MTL. These supports are specialist and wide-ranging, covering information, advice, dementia care assessment and planning, practical in-home supports that personalised, individualised and flexible support. They are provided by a small team of highly qualified, experienced and dedicated multidisciplinary team, supported by trained DSWs. Despite the upward trend in referrals and expansion of supports on offer, funding for Living Well with Dementia has remained constant since 2016.

Living Well with Dementia has a large number of strengths. People with dementia, family care and health professionals were very proud to have an innovative service of such high quality and standing in their locality and would like to see the service adequately resourced and the model extended to other areas. However, Living Well with Dementia faces a number

of challenges that need to be strategically planned. These include the increasing demands for its services and lack of staff capacity within Living Well with Dementia to effectively provide supports and meet demand, which have funding implications. Increasing staff capacity will help with addressing issues related to the geography of South Tipperary and enable the service to effectively reach more people across the area. However, longer-term strategic planning in relation to staff recruitment, retention and succession planning is needed. Issues in relation to the building in which Living Well with Dementia in South Tipperary is located were also identified as a challenges that needs urgent attention.

Managerial change and FCI's decision to withdraw its role in facilitating and managing the service have been the biggest challenge for Living Well with Dementia and threaten the sustainability of the service beyond 2023. While the OT and MTL are to come under the HSE's remit, there is still the urgent matter of securing a host organisation for the nurse and DSW service. Staff in Living Well with Dementia tasked with this are at the time of writing in discussions with a potential host organisation. Close working relationships with the HSE and other organisations have been vital to the success of Living Well with Dementia to date and are key to its success in the future.

The recognition and support that the HSE have given to the service since 2012 has not gone unnoticed and is highly valued by all stakeholders. HSE support is therefore seen as a major opportunity for Living Well with Dementia. However, this must be seen in the context of the contribution that Living Well with Dementia makes to the HSE through its role in implementing national policies and programmes and its close alignment with the HSE's new Model of Dementia Care in Ireland. In this context, there may be opportunities to channel funds to Living Well with Dementia through national level funding aimed at improving memory assessment and support services and develop integrated pathways between diagnostic and post-diagnostic supports.

Recommendations

Recommendation 1: Ensure the immediate sustainability of all four components of Living Well with Dementia in South Tipperary as a matter of urgency

FCI's decision to cease its facilitation of Living Well with Dementia in South Tipperary at the end of 2023 makes sustainability an urgent matter. While the OT and MTL are to come under the HSE's remit, there is still the urgent matter of securing a host organisation for the nurse and DSW service. This is a matter of urgency.

Recommendation 2: Secure a guarantee from South Tipperary University Hospital with respect to Living Well with Dementia in South Tipperary's tenancy in the building in which it is currently located as a matter of urgency

Recommendation 3: Expand the capacity of Living Well with Dementia

It is important to expand the capacity of Living Well with Dementia in South Tipperary for supports to be effectively delivered and to meet the increasing levels of demand for its supports. There is a strong case for appointing a full-time service manager to

provide operational management and strategic leadership and a part-time clerical staff member for administrative support.

Recommendation 4: Develop a five-year strategic plan setting out clear goals, priorities and strategies for ensuring the longer-term sustainability of Living Well with Dementia in South Tipperary.

Recommendation 5: Identify a sustainable funding mechanism and develop a multi-annual financial plan for Living Well with Dementia in South Tipperary.

Recommendation 6: Consider re-establishing the Dementia Consortium for a set period to engage with stakeholders including people with dementia and family carers and harness support

Recommendation 7: Ensure a permanent home for Living Well with Dementia in South Tipperary

Recommendation 8: Develop a staff recruitment, retention and succession plan

Recommendation 9: Explore the potential for leveraging funding sources such as funding for development of MASS or funding for implementation of Sláintecare

Chapter 1: Introduction

Living Well with Dementia in South Tipperary⁴ has established itself as a fundamental, yet dynamic, support service for people with dementia and their families in the area. It originated in 5 Steps to Living Well with Dementia in South Tipperary, one of four demonstrator projects that was established in 2012, having been awarded funding under the Health Service Executive (HSE) & Genio Dementia Programme. The overall aim of this study when initiated in 2022 was to provide evidence to help inform future development and sustainability of the service and to incorporate the views and perspectives of people with dementia and their family carers. The objectives of the study were to:

- Succinctly describe the evolution of the Living Well with Dementia Service over the years 2012 to 2022
- Provide an overview of the supports that the service is currently providing to include an outline of the role and contribution it is making to implementing the National Dementia Strategy and an assessment of how well the service aligns with the HSE's emerging Model of Dementia Care
- Outline the role and contribution that the service makes to the lives of people with dementia and their family carers using the service, including from the perspectives of people with dementia and their family carers
- Provide an overview of how the service currently operates and where it is currently at with respect to existing resources, skills, and alliances, including an assessment of strengths and weaknesses, and its positioning within the national, regional, and local dementia ecosystem
- Identify opportunities for change within the environment in which the service operates and identify any constraints external to the service that are limiting opportunities for change

The sustainability of the service has taken on greater significance since the study commenced. When funding for the original demonstrator project came to an end in 2015, continuation of the service was made possible with support from Family Carers Ireland (FCI) and funding from the HSE. In October 2015, FCI took on the role of facilitating and managing the service, under a Section 39 grant aid agreement reached with the HSE. This arrangement between the HSE and FCI has worked well. Funding from the HSE together with FCI's role in managing the service have been vital for sustaining the service. Following restructuring within FCI in 2021, the service moved from being locally managed to being managed at national level from Tullamore. These changes and their impacts on Living Well with Dementia were explored in interviews with staff and relevant stakeholders and will be discussed in this report. While the study was still underway, a decision was taken by FCI in January 2023 not to pursue a new Section 39 grant aid agreement with the HSE, which will effectively bring its role in facilitating and managing Living Well with Dementia to an end in December 2023. A decision has been taken by the HSE to bring two of the four components of Living Well with Dementia - the Senior Occupational Therapist (OT) and Memory Technology Library (MTL) under the remit of the HSE. The other two components - the Dementia Nurse and Dementia Support Worker (DSW) service - will continue if a new host

⁴ For brevity, Living Well with Dementia in South Tipperary will be referred to in the remainder of this report as Living Well with Dementia.

organisation can be found to take over from FCI. The responsibility for finding a new host organisation was given by the HSE to staff at Living Well with Dementia who at the time of writing are in discussions with a potential host organisation. While negotiations are ongoing, these two components of Living Well with Dementia continue to be in a highly precarious and uncertain position. At the same time, a new Model of Dementia Care in Ireland (HSE, 2023), to which Living Well with Dementia is very closely aligned, has been launched by the HSE. It is in this context that this study takes on greater significance. This reports considers the implications of these changes for Living Well with Dementia, and identifies the challenges as well as the opportunities that the service is facing. It considers the steps that are urgently needed to ensure the sustainability of all four components of Living Well with Dementia in the future.

1.2 Structure of the report

The next chapter of this report (Chapter 2) outlines the methodology for the study. Chapter 3 describes how Living Well with Dementia originated in the 5 Steps to Living Well with Dementia in South Tipperary project and how it has unfolded over the years 2012 to 2022. Incorporated into this chapter are findings from a range of studies providing substantial evidence of its significance in the dementia care landscape, both locally and nationally. Chapter 4 provides an overview of Living Well with Dementia and what makes the service distinct. It describes the four main components of Living Well with Dementia (i.e., the Dementia Nurse Specialist, Senior Occupational Therapist, DSW service, and MTL) and the respective roles of the small team of health professionals at the service. It presents service level data on referral trends, service use and service funding. For this study, interviews were conducted with people with dementia, family carers, health professionals and other stakeholders. Chapter 5 presents their perspectives on the service components offered by Living Well with Dementia. Study participants also highlighted a range of issues and challenges facing Living Well with Dementia. These are outlined in Chapter 6 and include increasing demand, issues related to staffing, funding, geography, organisation and positioning, the premises in which the service is housed and co-location. Chapter 7 presents a synthesis of the findings and draws some conclusions. A set of recommendations are then presented.

Chapter 2: Methodology

This study is a mixed-methods study conducted over a six-month period (September 2022 to February 2023). Qualitative methods were used to explore the experiences and views of study participants including health professionals and DSWs at Living Well with Dementia, people with dementia and family carers, and a range of other key stakeholders. A combination of focus groups and individual interviews were conducted to explore the experiences and views of these participant groups. With permission of participants, interviews and focus groups were recorded. They were transcribed and analysed using thematic analysis. The study included a review of service activity and expenditure data and an analysis of a small number of evaluation forms completed by people with dementia and family carers.

2.1 Focus groups with staff at Living Well with Dementia

One focus group was held with health professionals and one with DSWs working at Living Well with Dementia. Both focus groups took place in the MTL on the grounds of South Tipperary University Hospital (STUH), Clonmel. Three health professionals working at Living Well with Dementia and five DSWs participated in the focus groups.

2.2 Focus group with people with dementia

One focus group was held with people with dementia who attend Let's Talk, a peer support group of people with dementia facilitated by health professionals at Living Well with Dementia. Three people with dementia attended and participated in the focus group, which took place in the MTL on the grounds of STUH, Clonmel. These participants took an opportunity in the focus group to ask questions of the researcher about the availability of peer support groups in other parts of the country.

2.3 Interviews with people with dementia and family carers

Although we do not have a detailed profile of people availing of Living Well with Dementia supports, we devised a sampling frame to guide the identification of people with dementia and family carers for participation in the study. To get the views of a diverse spread of people with dementia and their family carers and to avoid bias in selection, we sought to include people who differed by age, gender, family type, living situation, and location. The sampling frame was used by health professionals at Living Well with Dementia to select a sample of people with dementia and family carers to be invited to participate in the study. These potential participants were contacted by Living Well with Dementia and asked if they were agreeable to having their names included on the list and permission was sought to have their names and contact details shared with the researchers.

Six people with dementia and 18 family carers were invited to participate in an interview. One person with dementia declined to take part due to a family bereavement. Two family carers declined without giving a reason. It was not possible to make contact with one person with dementia and another interview did not go ahead as the person could neither recall having been invited to interview nor receiving supports from Living Well with Dementia. Two family members asked if the person with dementia to whom they provided care could be included in the interview. In total, five people with dementia and 16 family carers participated in an interview. Two of the interviews were joint interviews with people with dementia and their family carer.

Interviews were mostly conducted in person and took place either in people's homes or at the MTL. Telephone interviews were conducted with two family carers who lived in areas other than South Tipperary and one interview was conducted by Zoom at the request of the family carer.

The interviews explored the experiences of people with dementia and family carers of using supports and services offered by Living Well with Dementia.

2.4 Interviews with relevant stakeholders

A list of relevant stakeholders was compiled by health professionals at Living Well with Dementia who contacted each stakeholder to obtain permission to be included on the list and share their names and contact details with the researchers. Stakeholders were invited by email to participate in a one-to-one interview. All responded to the invitation and agreed to participate in an interview. For one stakeholder who was unable to participate due to family circumstances, a nominated person participated in this health professional's place. Most interviews were conducted online using Zoom, with a small number taking place in person or by telephone at the stakeholders' request.

At the interviews, stakeholders were invited to reflect on their knowledge and experience of Living Well with Dementia and collaborating with it, and to identify strengths and weaknesses of the service as well as any constraints on the service and opportunities for change.

2.5 Review of service activity and expenditure data and service user evaluation forms

A review of service activity and expenditure data was conducted and the findings are included in this report. A small sample (n=7) of short evaluation forms completed anonymously by service users were analysed.

2.6 Synthesis of findings

Data collected from the various sources were analysed separately and the findings were synthesised.

2.7 Ethical approval

Ethical approval was granted by the HSE South East Area Research Ethics Committee in September 2022.

2.8 Profile of study participants

Table 1 presents an overview of the sample achieved in the study. A total of 47 persons participated in either a focus group or a one-to-one interview.

Table 1: No. of study participants

Study participants		Number
Staff at Living Well with Dementia in South Tipperary	Senior health professionals	3
	Dementia support workers	5
Service users	People with dementia	8
	Family carers (current and former)	16
Other stakeholders		15
Total		47

The interviews with people with dementia and family carers reflect the quite diverse profile of people availing of supports and services offered by Living Well with Dementia. They included men and women, people of different ages from the younger (under 65 years) to the oldest-old (85 years and over) age groups, people with different living arrangements, different family circumstances and from different geographical regions within South Tipperary. Living Well with Dementia supports people with mild/moderate or more severe dementia progression, and caters for people with different levels of cognitive and physical abilities, different types of dementia, and people with and without insight into their condition.

A wide range of stakeholders (n=15) participated. Stakeholders interviewed belonged to two distinct groups. The first were health professionals (n=9) working in a variety of health services in South Tipperary. Health professionals participating included a general practitioner (GP), a public health nurse (PHN) who had consulted with other PHNs on her team in advance of the interview, Advanced Nurse Practitioners (ANPs) working in the Memory Clinic, Community Mental Health team or in STUH, an OT on the Community Mental Health team, an ASI Dementia Advisor, two old age psychiatrists and a geriatrician. The second group of participants were representatives from the HSE (n=3) and FCI (n=2) who held a managerial role (either currently or formerly) locally, regionally, or nationally.

Chapter 3: Living Well with Dementia: Origins and Evolution

3.1 Introduction

Most people with dementia wish to continue living in their own homes for as long as possible. Irish government policy has supported this preference for more than three decades. Ireland's National Dementia Strategy (NDS) states that: "People with dementia should be facilitated to remain living in their own homes and to maintain existing roles and relationships for as long as possible ..." (Dept. of Health, 2014 p.24). Yet, to date neither the service infrastructure nor the resources have been provided to achieve this espoused objective (Keogh and Pierce, 2017). The community care system for people with dementia in Ireland remains underdeveloped and fragmented and services provided tend to be characterised by inflexibility (Cahill et al., 2012). Against this background, small teams of health professionals and service providers in pockets across the country have been developing novel ways of working, seeking not just to improve but to transform the experiences of and outcomes for people with dementia and their family carers at a fraction of the cost of long-stay residential care and bypassing administrative inefficiencies.

One hub of innovation has been in South Tipperary. Responding to the situation locally in the 2000s, a group of health professionals from different disciplinary backgrounds came together and working with local organisations started to address service gaps. In 2008 the group established Le Cairde, a day care service for people with dementia, now operated by the Alzheimer Society of Ireland (ASI). The group also established a Memory Clinic in Cashel in 2009. Both services are still in operation in 2023.

The group were keen to build on their successes. On the South Tipperary Community Mental Health Team based in Clonmel, one member of staff had received a small amount of funding from Genio to develop a pilot project, providing high quality, flexible and individualised supports to people with mental health problems living in the community. The project got noticed by the HSE & Genio Dementia Programme, which at the time was developing and testing new service models aimed at improving the range and quality of community-based supports for people with dementia, with support from The Atlantic Philanthropies and the HSE (Genio, 2015). The project provided the inspiration for the development of a new project for people with dementia, 5 Steps to Living Well with Dementia in South Tipperary, the forerunner to Living Well with Dementia. In the next section, the 5 Steps to Living Well with Dementia project, which operated from 2012 to 2015, is briefly described. Two further periods in the evolution of Living Well with Dementia are then presented: 2015-2019 and 2020-2022.

3.2 The 5 Steps to Living Well with Dementia project (2012-2015)

5 Steps to Living Well with Dementia was one of four projects awarded funding in 2012 under the HSE & Genio Dementia Programme, following a national competitive selection process. The three-year project was awarded a total grant of €700,000, equivalent to a sum of €233,333 per annum. It was delivered by the South Tipperary Mental Health Services and led by Dr Caitriona Crowe, an old age psychiatrist. A Project Coordinator was appointed. The Dementia Consortium, a locally based group of organisations and individuals that bring varied expertise and resources to achieve a common goal, was a key feature of the HSE &

Genio Dementia Programme (Keogh et al., 2016). The Dementia Consortium created by 5 Steps to Living Well with Dementia in South Tipperary had 17 members including people with dementia, families and carers, health and social care organisations, other statutory organisations, voluntary and community groups, hospitals, nursing homes and many more.

5 Steps to Living Well with Dementia in South Tipperary supported people throughout all stages of dementia. The 5 Steps referred to people from before a diagnosis was made, when people were newly diagnosed, supporting people as the condition progressed, when people were in the advanced stages and at the end of life. The project developed and provided a broad mix of services and supports, including goal-focused and community connection programmes, intensive home supports and crisis intervention (Cullen and Keogh, 2018).

The years 2012 to 2015 may be described as a period of establishment and demonstration of the value of 5 Steps to Living Well with Dementia in South Tipperary. A key innovative element of 5 Steps to Living Well with Dementia was the DSW service, which has been positively evaluated (Cahill et al., 2014). The study found it to be a highly flexible and personalised approach to community-based support, yielding positive benefits for people with dementia and their family carers. People with dementia and their family carers were highly satisfied with the service. Following the evaluation, significant changes were made to the way in which the project's services were provided; it was developed into a five-arm model (O'Shea and Monaghan, 2016).

Service innovation in provision and utilisation of assistive technology and telecare in dementia care was a component of the HSE & Genio Dementia Programme (Cullen, 2020). As part of its approach, Fove Steps to Living Well with Dementia in South Tipperary successfully established a MTL in Clonmel, the first in the country. The original concept for the MTL, as described by Cullen (2020: 14), was 'to raise awareness of the potential of assistive technologies to help people with dementia and their families live well at home throughout their dementia journey'. As part of the MTL, a programme was developed to demonstrate and loan assistive technology to people with dementia and their family carers for a trial period, allowing individuals to test out a product and see how well it worked before deciding if they needed or wanted to buy it for themselves.

An evaluation of the overall HSE & Genio Dementia Programme found that, as one of the original four projects funded under the programme, 5 Steps to Living Well with Dementia in South Tipperary helped to develop and test new service models, increase the range and quality of community-based supports for people with dementia and improve the lives of people with dementia. It helped to demonstrate the practical feasibility of a community supports model in place of usual mainstream services. Importantly, it contributed to a shift towards a new paradigm for dementia in Ireland (O'Shea and Murphy, 2014).

Throughout its lifetime, the project had impressed on stakeholders that the project had an end date of October 2015. In its final year, the project focused on mainstreaming to ensure the sustainability of its initiatives after the HSE & Genio Dementia Programme grant funding ended. Areas identified for mainstreaming were: the Dementia Nurse Specialist, the DSW Initiative; the Community Connector; and the MTL, facilitated by an Occupational Therapist.

The MTL model was of considerable interest to other sites, and some (e.g. at Clonskeagh in South Dublin) began to develop a similar service (Cullen 2020).

Meetings were held to explore the potential governance, staffing and funding options for the continuation of 5 Steps to Living Well with Dementia in South Tipperary (O'Shea and Monaghan, 2015). The contribution of the project to the development and continued improvement of services for people with dementia in South Tipperary was acknowledged by the HSE. In recognition of its contribution, the HSE agreed to sustain these valuable resources and supports post-project end. An arrangement was made with FCI to deliver the service on behalf of the HSE through a grant aid agreement. This agreement ensured the sustainability of the service post-project end. To reflect the new arrangements, the project was renamed Living Well with Dementia in South Tipperary.

3.3 Living Well with Dementia in South Tipperary (2015-2019)

Since October 2015, funding for Living Well with Dementia has been provided by the HSE. The funding is made available through FCI, who took over responsibility for managing the service in October 2015. The Section 39 grant aid agreement between the HSE and FCI included funding for the post of a whole-time equivalent Dementia Nurse Specialist and for the continuation of DSW Initiative. It included funding for the continuation of the MTL and for its facilitation by an OT, a part-time post. The service during this period was locally managed by a Manager in the FCI Clonmel branch who worked closely with the HSE Local Manager for Older Person's Services and the nurses and OT in Living Well with Dementia.

Throughout this period, Living Well with Dementia continued to provide services developed by 5 Steps to Living Well with Dementia, with some adaptations. Chapter 4 presents an overview of the four main components – the nurse, OT, Dementia Support Worker service and the MTL – that come under the umbrella of Living Well with Dementia, highlighting the unique aspects of the service. Like its predecessor, Living Well with Dementia has continued since 2015 to expand the service options available to people with dementia and family carers. Examples of this expansion are given in Chapter 4. At the same time that the range of services was being expanded, the population covered was growing. Census data shows that South Tipperary had a population of 93,911 in 2016, when 1,251 people were estimated to be living with dementia (Pierce and Pierse, 2017). This is up from 1,010 in 2011 (Cahill et al, 2012), representing a 24% increase in the time period 2011 to 2016. The number is expected to double over the next 20 years.

During the 2015-2019 period, Living Well with Dementia made a major contribution to national service development for people with dementia and their family carers in Ireland in 2018 when a national Memory Technology Resource Rooms (MTRRs) programme was launched by the National Dementia Office (NDO). The MTL in Clonmel provided the concept and blueprint for this national programme. By the end of 2019, there were 25 MTRRs in operation across Ireland. The OT in Living Well with Dementia continues to play a central role in the national MTRR programme (Cullen, 2020), and the nurse and OT have worked jointly and collaborated with others to create a range of national resources, as outlined in Chapter 4.

3.4 Living Well with Dementia in South Tipperary (2020-2022)

Whereas the years 2015 to 2019 were a period of embedding the service in local infrastructure and expansion of the supports offered by the service, 2020 and subsequent years have been a time of upheaval for Living Well with Dementia, caused primarily by the Covid-19 pandemic, but exacerbated by management change in HSE and restructuring within FCI.

The first case of COVID-19 in Ireland was announced on 29 February 2020, after which an extensive range of public health, societal and economic measures to ‘flatten the epidemic curve’ and prevent the health care system from being overwhelmed were introduced and implemented across Ireland. Across Ireland and the world, the Covid-19 pandemic had a major impact on the capacity of health systems to continue the delivery of essential services. There is evidence that COVID-19 isolation measures negatively impacted on people with dementia and damaged the cognitive and mental health of people with dementia across the world and adversely affected family carers (Suarez-González et al., 2020; Suarez-González et al., 2021). Staff in Living Well with Dementia recognised how critical it was for them to continue delivery of services and supports to people with dementia and their family carers, one of the most vulnerable populations affected by the pandemic. Service level data presented in Chapter 4 gives an indication of the impact of the pandemic on Living Well with dementia, and how Living Well with Dementia responded.

As well as upheaval associated with the pandemic, changes took place at management level within both the HSE and FCI. The HSE Manager of Older Person’s Services for South Tipperary was replaced with a new manager. Following restructuring within FCI, the service moved from being locally managed to being managed at national level from its Head Office in Tullamore. These changes and their impacts on Living Well with Dementia were explored in interviews with staff and relevant stakeholders and will be discussed further in Chapter 6.

**DIAGRAM 1:
A BRIEF HISTORY OF
LIVING WELL
WITH DEMENTIA
IN SOUTH
TIPPERARY**



Chapter 4: Living Well with Dementia in South Tipperary: An Overview

4.1 Introduction

Living Well with Dementia is located on the grounds of STUH in Clonmel, a large town close to South Tipperary's border with County Waterford. Living Well with Dementia has three main aims:

- (1) to provide a single point of contact for dementia in South Tipperary;
- (2) to support people with dementia to live full, enriched, and happy lives at home within their communities for as long as possible; and
- (3) to improve the quality of life for people with dementia by providing individualised, high quality, flexible support.

Living Well with Dementia has four main components. These are:

- Dementia Nurse Specialist (DNS),
- Senior Occupational Therapist (OT),
- Dementia Support Worker (DSW) service, and
- Memory Technology Library (MTL).

The chapter describes each of these key components and the respective roles of the small team of health professionals. It explains how the components fit together under the umbrella of Living Well with Dementia to form a unique service. The chapter draws on focus group interviews with staff at Living Well with Dementia and other service information available including service activity data relating to referrals, assessment and service use, service user evaluation forms, and data on expenditure.

The team at Living Well with Dementia includes a Dementia Nurse Specialist⁵ (1.0 whole time equivalent (WTE) post shared by two nurses) and Senior Occupational Therapist⁶ (0.6 WTE post) who are highly knowledgeable, experienced and skilled in dementia care and extremely motivated. The nurse and OT have multiple roles at Living Well with Dementia. This chapter outlines the respective roles that the nurse and OT play in relation to referrals and point of contact; assessment; and information, advice, and practical support. Throughout this chapter, the interdisciplinary way in which the nurse and OT work to support people with dementia and their family carers is highlighted. The team is supported by approximately 16 trained Dementia Support Workers (DSWs). The chapter describes the DSW service offered by Living Well with Dementia. It provides an overview of the MTL, and the multiple other uses of the building in which the MTL is housed, including as a venue for the delivery of practical psychosocial interventions to individuals and their family carers. The chapter shows that, as part of their role, the nurse and OT have been continually developing services and expanding on supports offered by Living Well with Dementia including a range of group

⁵ For the remainder of this report, the term nurse is used to refer to the Dementia Nurse Specialist at Living Well with Dementia.

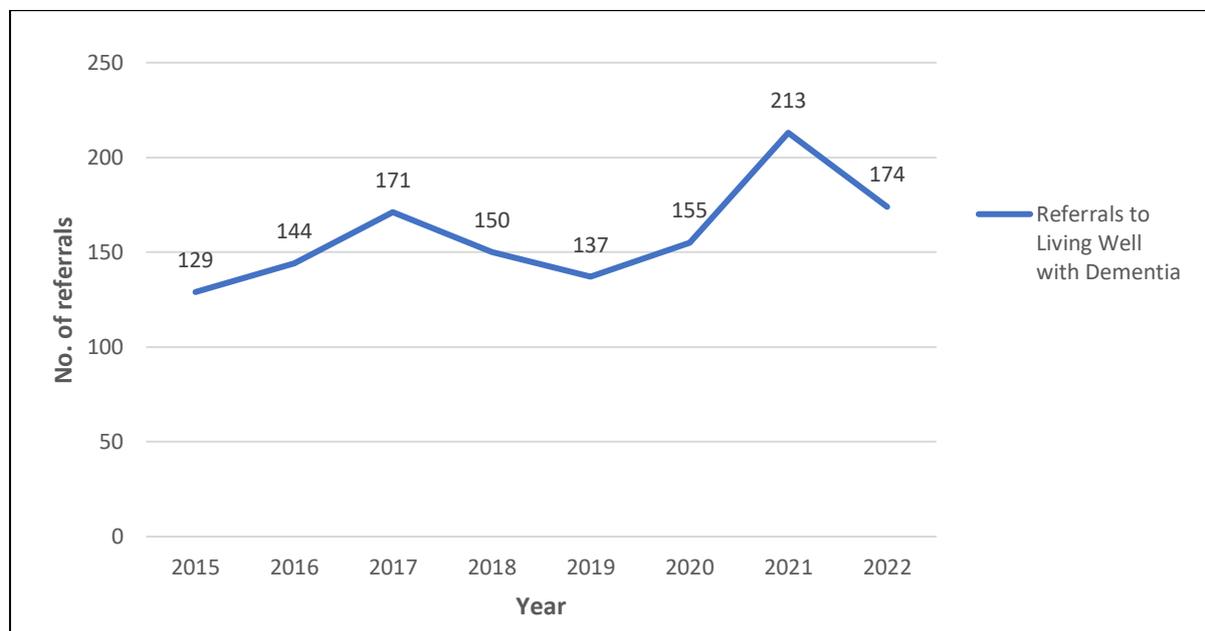
⁶ For the remainder of this report, the term OT is used to refer to the Senior Occupational Therapist at Living Well with Dementia.

psychosocial programmes, which are briefly described. The chapter provides a brief overview of the collaborations in which the clinicians have been involved to create national resources and the leadership role played at national level in relation to the HSE's MTRR's Programme. Finally, it presents data on expenditure for delivery of the services offered by Living Well with Dementia.

4.2 Referrals and point of contact

A person with dementia or their family carer in South Tipperary can self-refer to Living Well with Dementia or be referred by a health professional. The referral form gives the referring person options to make a referral for: (i) dementia nurse specialist including dementia support worker service; (ii) OT including Memory Technology Library; (iii) post diagnostic programmes; and/or (iv) carer education programmes. The nurse logs referrals, acts as a point of contact for persons referred and referring organisations, and manages referrals. A separate referral form developed by the National MTRR programme is also available for use to refer a person directly to the MTL and these referrals are managed by the OT. The nurse and OT spend a significant amount of time answering phone queries from people with dementia and their family carers and a significant amount of time liaising with health professionals and organisations referring service users. There is no administrative support at Living Well with Dementia for this. While data on the number of referrals are available, data on the large number of phone enquiries and time spent on these and follow up are not available due to lack of time and resources needed to record this data.

Figure 1: No. of referrals per annum to Living Well with Dementia in South Tipperary, 2015-2022



Notes: Figure for 2015 is an estimate based on 43 referrals between 02.09.2015 and 31.12.2015.

Source: Living Well with Dementia in South Tipperary

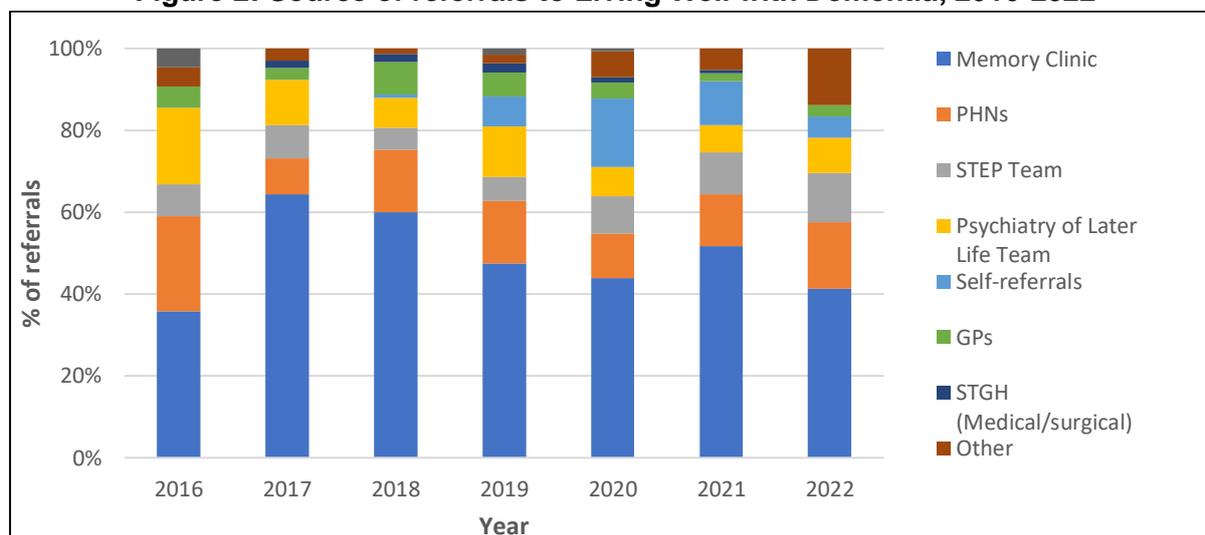
Figure 1 shows the number of referrals to Living Well with Dementia for the years 2015 to 2022. Referrals have fluctuated between 2015 and 2022. The highest number of referrals was reached in 2021 when 213 direct referrals were made. There were 174 in 2022, and while this number is lower than in 2021, it represents a 34.9% increase on referrals made in

2015, indicating an overall upward trend. The overall increase in the number of referrals means that the nurse is spending an increasing amount of time managing referrals and liaising with individuals and with many different health professionals and organisations making referrals (Figure 2) with no administrative support.

Data is also available on direct referrals to the OT and MTL for the years 2021 onwards (not shown). Some 98 people were directly referred to the OT in 2021 and 147 in 2022. Taking all referrals together, there was a total of 321 referrals to Living Well with Dementia in 2022.

Figure 2 shows the source of referrals to Living Well with Dementia for the years 2016 to 2022. It shows that referrals are from a range of sources. The highest relative proportion of referrals each year is from memory clinics. The relative proportion of referrals from memory clinics varies over the period reviewed, making up just over one-third of referrals (35.8%) in 2016, almost three-quarters in 2017 and just over two-fifths (41.4%) in 2022. PHNs are another key source of referrals to Living Well with Dementia, making up 16.1% of referrals in 2022. There has been a steady increase in the relative proportion of referrals from the Psychiatry of Later Life (POLL) team in South Tipperary, rising from 7.9% in 2016 to 12.1% in 2022. The relative proportion of self-referrals has generally decreased over the period, reducing from 18.5% in 2016 to 8.6% in 2022. The South Tipperary Enablement Programme for Older People (STEP) team first started making referrals in 2018. Referrals from this team grew over the next two years reaching a peak of 16.8% in 2020, but since then have fallen and in 2022 was the source of 5.2% of referrals. In comparison to referrals from memory clinics and PHNs, referrals from GPs tend to be relatively low, with an average per annum of 4.4% over the seven-year period. Referrals from STUH are also relatively low, making up an average of 1.2% of referrals.

Figure 2: Source of referrals to Living Well with Dementia, 2016-2022



Source: Living Well with Dementia in South Tipperary

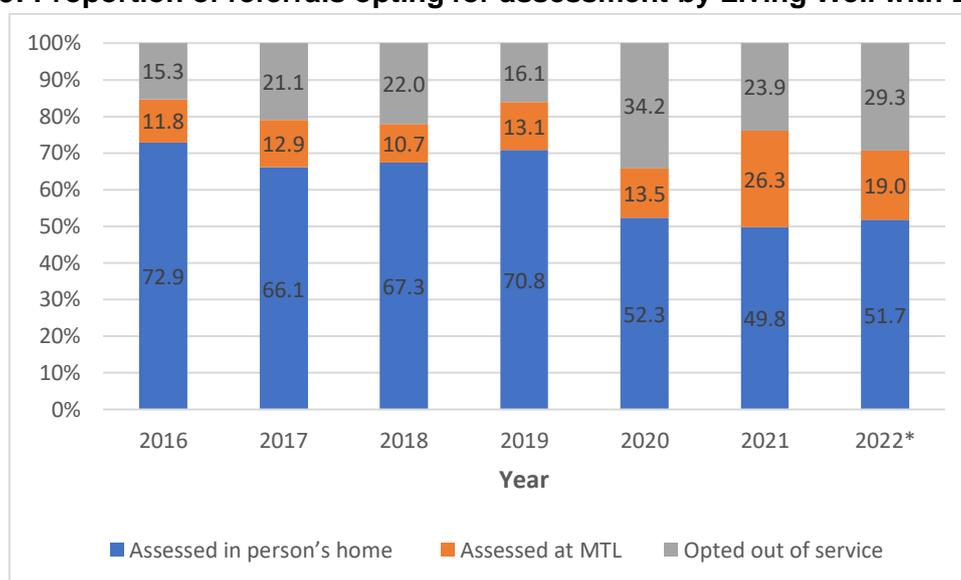
4.3 Follow-up and assessment

The nurse follows up each person referred to Living Well with Dementia with a telephone call, during which initial information and advice is provided to the person with dementia and/or their family carer. The nurse arranges for a person-centred assessment to be carried

out, if the person with dementia and their family carers are agreeable. While the nurse manages referrals and arranges assessments, the nurse and OT work closely together in assessing and supporting clients and providing relevant information and advice.

The majority of people referred opt in for an assessment, although the proportion varies considerably by year (Figure 3). The year with the highest proportion of referrals opting for an assessment (84.7%) was 2016. When contacted by the nurse, a person may choose to opt out of the service. The year with the highest proportion of people opting out of the service was 2020, when just over one-third (34.2%) of people referred opted out, and gives some indication of the profound impact of the Covid-19 pandemic on service take-up. Opt-outs remained relatively high in 2021 and 2022 (Figure 3), suggesting that the Covid-19 pandemic is continuing to have an impact on service take-up, and this may have repercussions in years to come.

Figure 3: Proportion of referrals opting for assessment by Living Well with Dementia



Source: Living Well with Dementia in South Tipperary

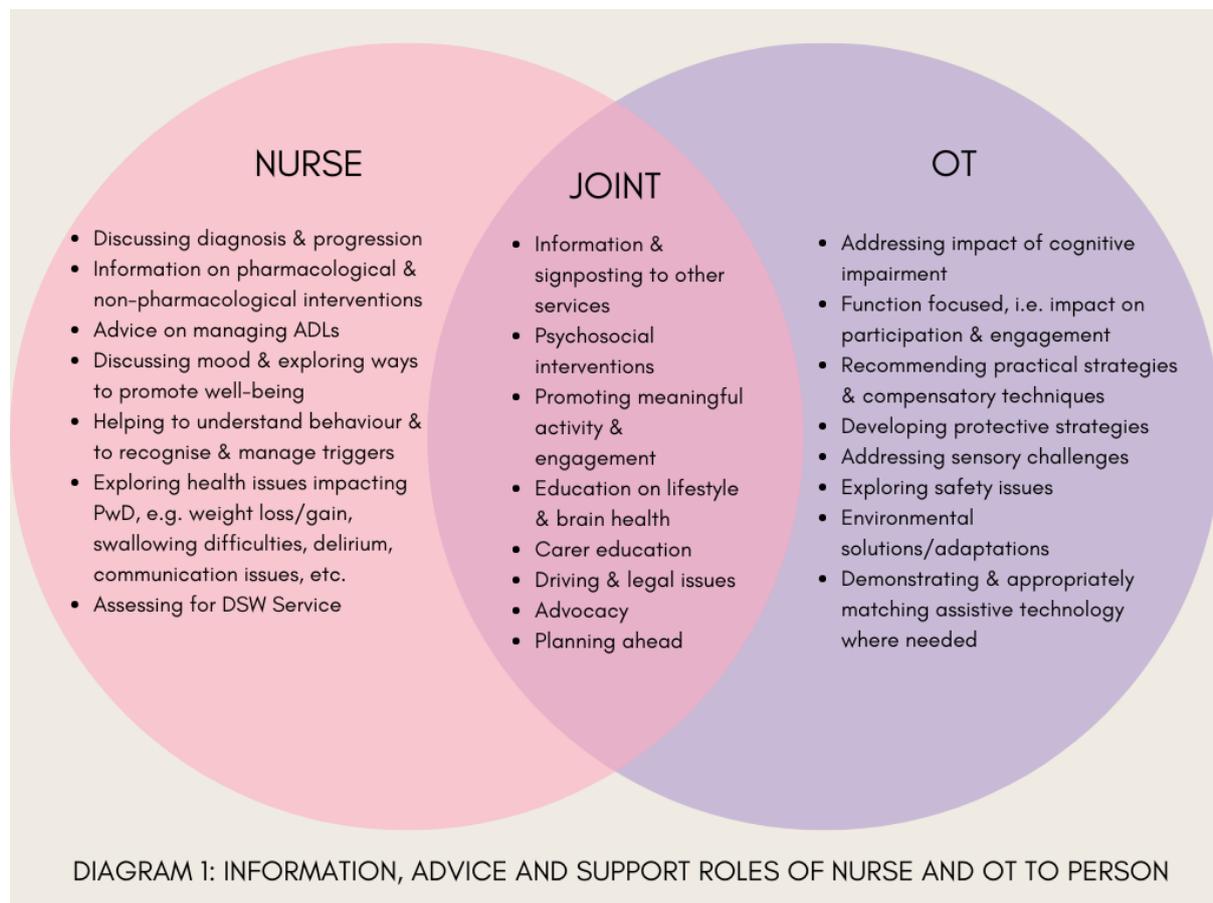
When a person referred opts into the service, the nurse usually arranges a home visit to carry out an assessment and provide further information and advice relevant to the particular circumstances of the individual and their family. On occasion, the home visit can involve a joint visit by the nurse and OT. Alternatively, where appropriate, it can take the form of a joint consultation at the MTL. Where the nurse or OT undertake an individual session in the person's home or at the MTL, each can make a referral to the other, if required. Referrals managed by the nurse in Living Well with Dementia include referrals for its DSW service, which is examined in Section 4.6.

4.4 Information, advice and practical support

Opting into Living Well with Dementia is important as it provides people with dementia and their family carers access to both the nurse and OT who have distinct but complementary roles, and as stated above, work closely together as an interdisciplinary team to support service users (see Diagram 2). The nurse acts as a single named point of contact at Living Well with Dementia and is available to address strategies for coping with a dementia diagnosis, provide information, and provide advice on an extensive range of issues (see

Diagram 2). These have all been identified in the HSE’s Model of Dementia Care in Ireland as important areas of consideration relating to post-diagnostic support for people with dementia and their family carers (HSE, 2023a). The nurse also identifies and signposts clients to other local supports and services.

The OT too has multiple roles (Diagram 2), which include helping the person to continue with their usual day-to-day activities, providing strategies to enhance cognitive function, advising on environmental adaptations and modifications and equipment to improve wellbeing, safety and functioning, as well as promoting brain health. In line with the HSE’s Model of Dementia Care in Ireland (HSE, 2023a), the information and advice provided by the nurse and OT is individually tailored and practical.



As with referral management and assessment, the work involved in providing information, advice and practical support to people with dementia and their family carers requires a significant investment of time by the nurse and OT, which is ongoing as the person’s dementia progresses. As part of this work, the nurse liaises with a wide range of other health professionals and services locally. These include primary (GP and PHN) and community care services; the POLL team; the STEP team; staff in STUH; the Memory Clinic in Cashes; the ASI including Dementia Advisor and Le Cairde Day Care; FCI; Sage Advocacy; Local Day Care Centres & Resource Centres; the Social Prescriber in Clonmel; and ALONE. The OT too liaises with a wide range of health professionals and, in the focus group, gave examples of joint working and sharing resources with the Dementia Advisor and support coordinators in ALONE and the National Council for the Blind in Ireland. The clinicians

placed a lot of emphasis on connecting with and building relationships with health professionals in these and other services in South Tipperary.

4.5 Dementia Support Worker (DSW) Service

The DSW service offers home support to people with dementia and is aimed at enabling people to remain living at home independently, building relationships and connecting them to the communities in which they live. The nurse in Living Well with Dementia oversees the DSW service. When a referral for the DSW service is received, the nurse undertakes an assessment to establish what need, if any, there is for a DSW and the type and level of intervention required. The nurse visits the person’s home to assess their day-to-day functioning. This includes assessing Activities of Daily Living and the person’s ability to participate socially at home and within their community. When assessed as needing a DSW, the nurse evaluates how the person might be supported to continue their engagement with activities and what level of support is needed. This involves goal setting with the person’s input. The nurse is responsible for identifying and allocating a suitable DSW. Usually, the person is placed on a waiting list until a DSW becomes available and hours can be allocated. FCI are notified of allocation of hours. The nurse continues to play an oversight role after a DSW has been allocated. The nurse regularly reviews the intervention and adjusts it as appropriate. This involves liaising with the person with dementia, family carers and the DSW. The nurse provides education and support to the DSWs.

Table 2: Average no. of clients supported and visits per month by DSWs

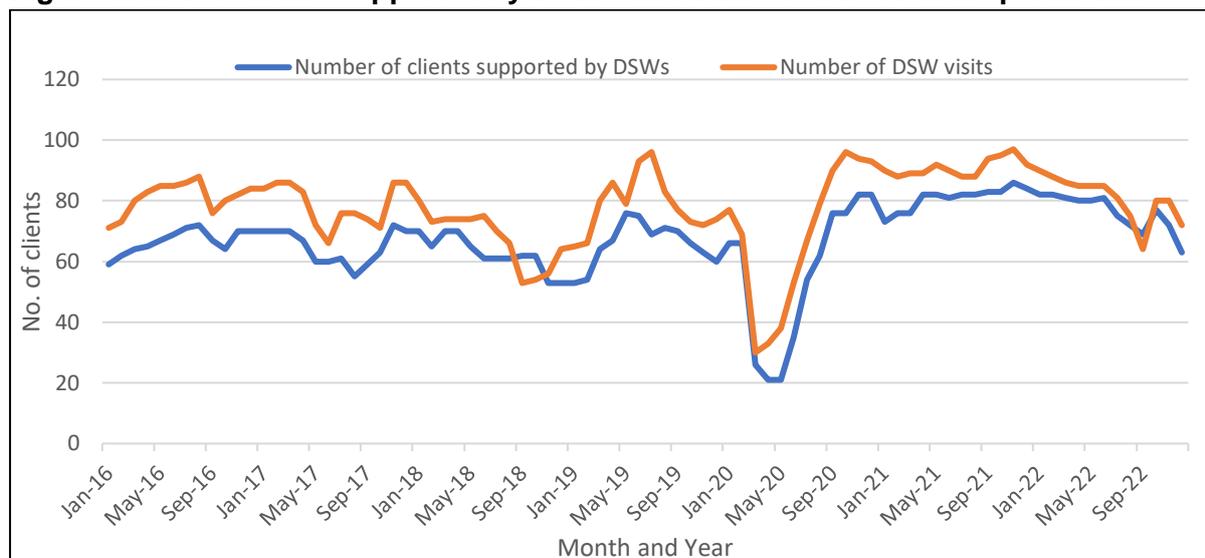
Year	Average no. of clients supported by DSWs per month	Average no. of DSW visits per month	Ratio of visits to clients
2016	67	81	1.2
2017	65	79	1.2
2018	63	68	1.1
2019	66	79	1.2
2020	56	68	1.2
2021	81	91	1.1
2022	76	81	1.1

Source: Living with Well Dementia in South Tipperary

Table 2 shows that the average monthly number of clients supported by a DSW in 2016 was 67. This figure remained similar for the years 2017, 2018 and 2019. However, In 2020, there was a lower average number of clients supported by DSWs per month, an indication of the profound impact the Covid-19 pandemic had on the service and people supported by it.

Monthly data shows the impact more clearly. Figure 4 shows that for 2020 the average number of clients supported by DSWs was 66 in both January and February 2020, but fell dramatically with the onset of the Covid-19 pandemic, when the number of clients supported fell to 26, 21, and 21 in March, April and May respectively.

Figure 4: No. of clients supported by DSWs and number of DSW visits per month



Source: Living with Well Dementia in South Tipperary

As essential workers, the DSWs were permitted to travel to and from work and continue to support people with dementia within their homes. From June 2020, the number of clients supports started to increase again and in November 2020, 82 clients were supported by DSWs, the highly number of clients supported in any month since the service commenced in October 2015. The DSW service continued to support a higher than average number of clients throughout 2021 and 2022 (Table 2 and Figure 4), reflecting the higher need as a consequence of the Covid-19 pandemic. While the DSW service initially expanded to meet the increased demand and need, from June 2022 service provision was cut back due to budgetary constraints, leaving some clients without a DSW or with a reduced number of hours.

DSWs participating in a focus group described the activities they do with people with dementia including reminiscing about past times, writing down sayings, chatting about hobbies or interests they had, watching football together, playing cards, doing jigsaws, listening to music and sing songs, baking, crocheting and gardening. Many people with dementia they supported liked going out of the house for walks around the local neighbourhood, to the church, or to go shopping or to a coffee shop. It gave them the opportunity to meet other people and experience life outside the home.

“... people will come up to them and say hello to them. They might not recognize who they are but they will figure it out or the person will tell them. They love that. The last day I brought a guy to ... where he went to school and he absolutely loved it. He wanted to go in. He said my photograph is on the wall somewhere and we went in and found the photograph. He was absolutely thrilled.” [DSW005]

DSWs also support people with dementia in more practical but equally important ways, such as ensuring that they kept hydrated during hot weather, that the heat was turned on to keep them warm in the cold weather, or ensuring that they had eaten by heating up meals

delivered by Meals on Wheels. Though not intended as part of their role, DSWs helped people with dementia with personal care if needed during their visits.

DSWs perceived that their visits helped to lift a person's mood and that this was especially important for people with dementia who were isolated, living alone, or experiencing a bereavement following the death of someone close. They also perceived it to be important for people with dementia experiencing low mood or depression, and believed that spending time with a DSW could prevent a person with dementia going further into depression.

“A lot of their relatives would say “he was in a bad way before you came in but God you gave him a great lift”. A lot of them say that and it lasts for hours. They mightn't talk to their spouse but they can talk to us about little things. I find that.” [DSW005]

“Some of the families would say “they are in great form for the rest of the day after you being here’. It kind of goes on. It does last.” [DSW002]

DSWs described Living Well with Dementia as “more social” than other services and highlighted the importance for people with dementia of friendship and having someone to talk to and share any worries or concerns.

“It is not essential [personal] care. They need something else. We feel more like a friend than anything else. They need that ... I focus more on the social engagement with them rather than activities. They want to be seen, they want to be heard. They want to matter. That is all they want and it is not that difficult to see really.” [DSW001]

DSWs would like to see more input into the care of people with dementia from GPs, PHNs and for people with dementia to have greater access to other health professionals such as for eye checks and hearing checks. DSWs would like to see the DSW service model used for people with conditions other than dementia that prevented them from getting out of the house.

DSWs stressed that their work involved providing support for family carers, some of whom are providing care around the clock. They identified this dual purpose – providing company to people with dementia and a support network for family members - as the main strength of Living Well with Dementia. DSWs recognised that for family members, caring for a person with dementia can be tiring and demanding, physically, psychologically and emotionally, which they felt was not often recognised and that family carers needed time for self-care. Support for family carers from DSWs included providing information, reassuring them when they are worried and giving them a break.

“When you come, they [family carer] are worried about something, they can say ‘Is this normal? Can I get help somewhere?’ A little chat. They might not see anyone for the week and they can go on off for their walk, go off to bed.” [DSW002]

DSWs found that some family carers, especially older family carers, had difficulty navigating the health and social care system, and they would support them with this:

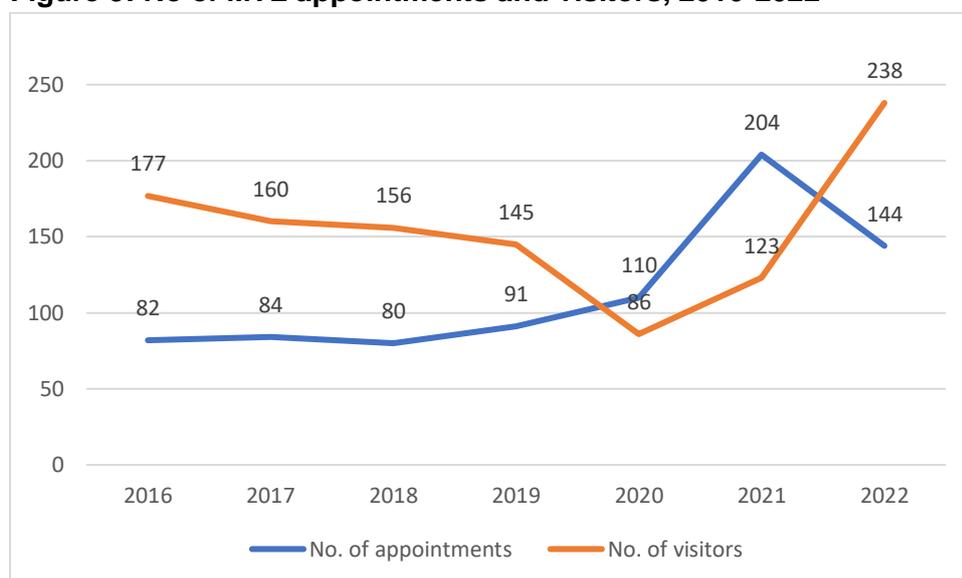
“I have phoned the PHN on his behalf many a times, because he just doesn’t know what services are available or what he is entitled to ... I pick up the phone because he is overwhelmed and he doesn’t know what to say and get confused and gets flustered, so I phone on his behalf or contact the nurses to do it on his behalf.”
[DSW002]

DSWs described their work as important and rewarding, but stressed that it also had its challenges, which are outlined in Chapter 6, Section 6.3, from the perspective of DSWs, family carers and health professionals.

4.6 Memory Technology Library

The MTL is housed in a building on the grounds of STUH in Clonmel. The original concept for the MTL has been described in Chapter 3. When it originated, the MTL service had important aspects (Cullen, 2020) which continue to be important to this day. First is that the MTL is facilitated by an OT, who is skilled in supporting persons with dementia and their family carers and has a good knowledge of the therapeutic benefits and precautions of available assistive technologies. Second is that the MTL offers a welcoming, person centred consultation that is easy to access, at a time when people need it. The OT provides demonstration of a range of assistive technologies and the MTL offers a loan facility for some technologies for people with dementia and their family carers to try before deciding on whether to purchase.

Figure 5: No of MTL appointments and visitors, 2016-2022



Source: Living with Well Dementia in South Tipperary

Figure 5 shows the number of appointments at and visitors to the MTL for the years 2016 to 2022. Since October 2015, there has been 795 appointments with the MTL and 1,085 individuals have visited the MTL. The trends in the number of appointments has been upwards, increasing from 82 in 2016 to 144 in 2022. The year with the highest number of appointments was 2021 when there was 204 appointments. In 2020 and 2021, the MTL facilitated appointments through phone and video call as well as in-person visits.

The desired outcome of the MTL remains the same as when it first started, i.e., that service users find the information and advice useful, supportive and practical to implement. Based on analysis of a small sample (n=7) of evaluation forms completed by family carers and people with memory problems and dementia, feedback on appointments and visits to the MTL was overall extremely positive, with the majority (6/7) stating that the visit was very useful. Reasons given for its usefulness were the practical support provided, increased awareness and knowledge of the AT available and the possibility of getting AT equipment on loan. Visitors also highlighted the importance of being able to talk to and discuss issues with a clinician who could give professional advice, provide insights into dementia, advise on how to support the person with dementia and improve their quality of life. This left them feeling supported.

“Staff provided valuable insights into how to care for a person with dementia, advice on what aids might be useful to improve quality of care and everyday life, provided with materials to take away. Felt listened to understood and empowered by OT.”
[MTL visitor feedback]

Most visitors (6/7) stated that they found the ATs useful and referred to a wide range of AT equipment they found useful. They also found the information and advice provided about engaging people with dementia in meaningful activities very useful. Visitors found it very reassuring to know that they could make a return visit should the need arise in the future. Apart from one visit, which was challenging because the person with dementia was reluctant to accept the diagnosis or the need for any support, visits were reported to be successful and a positive experience.

An important aspect of the OT role since 2015 has been to continually develop MTL services in response to identified need. The OT have been involved in several collaborations. One example is a research collaboration with WRC on GPS (Global Positioning System) use with people with dementia. The collaboration resulted in multiple resources and outputs including the development of an AT evaluation tool; Product Information Sheets; simple strategy handouts, adapting smartphones; identification of a selection of Apps; and a GPS Guidance Document. Collaborations have also led to the development of guides and booklets which are available nationally as a resource to people with dementia and their families. These include *The Memory Guide*, the *At Home Activities Booklet* developed as a national resource for the NDO during the Covid-19 pandemic, and *The Supportive Memory Guide: Empowering You with Practical Tips and Useful Technologies*, an e-book (see Table 3).

Table 3: National resources developed by staff at Living Well with Dementia in collaboration with others

Title	Cover image	Developed by	Link
<p><i>The Memory Guide</i></p>		<p>NURSE and OT at Living Well with Dementia and social worker in South Tipperary</p>	<p>https://dementiapathways.ie/filecache/ce21795/1603-memory-guide-tipperary.pdf</p>
<p><i>The At Home Activities Booklet</i></p>		<p>OT for the NDO</p>	<p>https://www.hse.ie/eng/services/news/newfeatures/covid19-updates/partner-resources/at-home-activities-for-people-with-dementia-families-and-carers.pdf</p>
<p>An eBook: <i>The Supportive Memory Guide: Empowering You with Practical Tips and Useful Technologies</i></p>		<p>Three OTs and Digital Designer</p>	<p>https://www.ehealthireland.ie/additional-resources/supportive-memory-guide/supportive-memory-guide.html</p>

As well as housing the MTL, the premises on the grounds of STUH has multiple other uses. It provides office space for the nurse and OT and provides a base from which they can work. The MTL rooms double up as meetings rooms, where the nurse and OT can conduct assessments, and hold information and advice sessions with individuals and their family members. The rooms are also used by the nurse and OT to provide education and support to the DSWs, to meet with health professionals and host other visitors to Living Well with Dementia. The MTL provides a venue for the delivery of a range of group psychosocial programmes developed jointly by the nurse and OT, which are the subject of the section that follows. The group programmes offer another example of how clinicians at Living Well with Dementia work in an interdisciplinary manner to continually develop the service.

4.7 Group programmes

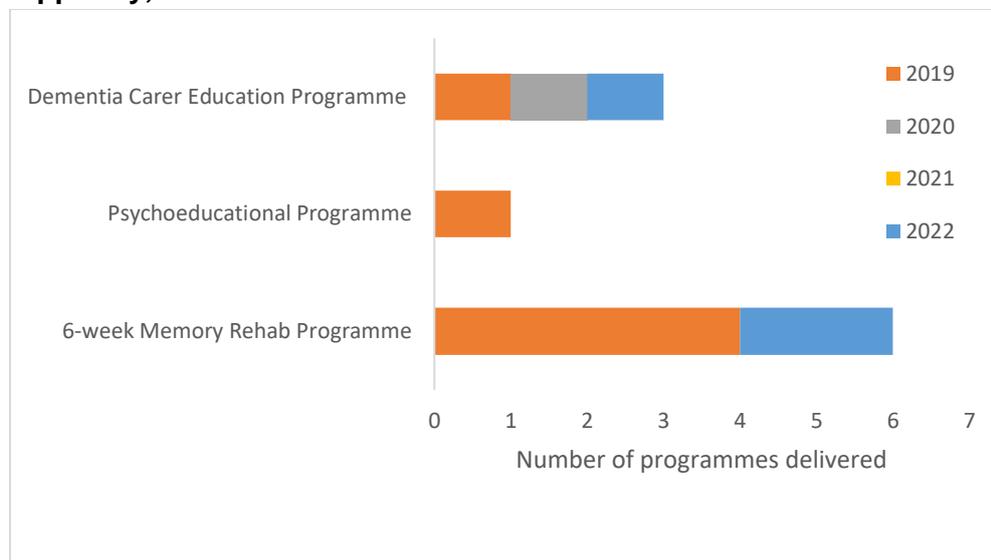
As mentioned above, the OT and nurse have worked jointly in developing a range of group psychosocial programmes for delivery at the MTL. Much of this work was made possible by once-off funding from Dormant Accounts awarded by the NDO (of up to €25,000) to Living Well with Dementia and 16 other projects in 2018. The funding covered staff costs to develop and deliver post-diagnostic support interventions to people with dementia and their family carers over an 18-month period commencing September 2018. Living Well with Dementia used the funding to develop a group-based Memory Rehabilitation Programme for people newly diagnosed with dementia and their family carers and a separate psycho-educational programme tailored for people who receive a late diagnosis of dementia and for their family carers. In an overall study of the implementation and impact of the HSE's Post-diagnostic Grant Scheme, cognitive rehabilitation interventions such as the Memory Rehabilitation Programme delivered in South Tipperary were found to be of value, especially for people in the early stages of cognitive impairment with the ability to retain or learn new information, and were reaching the intended target beneficiaries (Pierce et al., 2019). The grant funding was found to be crucial for enabling health professionals to introduce and deliver cognitive rehabilitation, psychoeducational and other post-diagnostic support interventions. It thereby enhanced service provision and supports for people with dementia and their family carers, and helped to establish such psychosocial interventions on a firmer and consistent footing (Pierce et al., 2019). However, concerns were raised about the time-limited nature and fixed level of income associated with funding from Dormant Accounts as it can place constraints on the sustainability of projects funded in this way.

Building on this work, the nurse and OT at Living Well with Dementia worked jointly and in collaboration with a social worker in South Tipperary to develop a guide, *The Memory Guide*, aimed at helping people understand their diagnosis of dementia and providing them with practical information to help manage symptoms and live well (Table 3). It also provides information and guidance on engagement in meaningful activities for people with dementia and links to resources. The guide is available to people throughout the country.

In addition to the programmes developed with funding from the HSE's Post-diagnostic Support Grant Scheme, the nurse and OT at Living Well with Dementia jointly developed other group based programmes including a Carer Education Group and Let's Talk Group. Let's Talk is a peer support group for people with dementia, jointly developed by the nurse and OT and facilitated by Living Well with Dementia. During the pandemic, it was not possible for Living Well with Dementia to offer its in-person group based supports and

services to people with dementia and/or their family carers during COVID-19. However, these groups programmes started running again in 2022 (Figure 6).

Figure 6: No. of group programmes delivered by Living Well with Dementia in South Tipperary, 2019-2022



Source: Living with Well Dementia in South Tipperary

The nurse and OT are also jointly involved in a range of other activities including providing education locally (e.g. community groups), and raising awareness and understanding of dementia. They have also worked jointly on the development and redesign of the Living Well with Dementia website (www.southtipperarydementia.ie), which involved collaborating with a web designer to create a clear platform about the services and with relevant resources, links and publications, that can be used nationally.

4.8 Collaborations and contributions at national level

In addition to their roles within Living Well with Dementia, the nurse and OT play an important roles at national level. The nurse and OT provided supervision to learners (Home Care Support Assistants working with people with dementia) on the pilot phase of the National QQI Level 5 Dementia Care & Support Home Care Education Programme, which is to be evaluated. The nurse and OT at the MTL have worked on collaborations and created national resources (Table 3). The OT is funded by the NDO through FCI to provide clinical leadership to the National MTRRs Programme, which involves a number of responsibilities and roles, as outlined in Box 1.

Box 1: Clinical Leadership to the National MTRRs: Roles and responsibilities of OT

- Identify service gaps and lead service development
- Share and enhance knowledge of dementia good practice and in-depth knowledge of AT e.g. GPS, Ethics guidelines etc.
- Mentor new MTRR staff when a new MTRR is developed. This involves offering onsite or virtual support for new MTRR staff members new to AT where such support is not available locally.
- Design and deliver in-depth high quality education workshops in response to an increasing need for health care professionals to understand the role AT can play in care packages and discharge from hospital. Educational workshops have been provided to health care professionals working in hospitals and to members of the Royal College of Physicians in Ireland, and OT students in Trinity College Dublin.
- Identify, organise and facilitate the delivery of training to the national MTRR network including training from key stakeholders in dementia, in-service training, product review series, and talks from national services/resources.
- Lead and support relevant working groups within the MTRR network e.g. promotional material, ethics guidance document, GPS at MTRR guidance document, Policies and Procedures etc.
- Act as a national resource for all MTRRs on AT/dementia/cognitive rehabilitation principles, activities, ethics, and dementia friendly environmental design
- Lead research on AT (GPS, Robotics etc.) which will support practice guidance that can be used nationally in particular keeping abreast with new emerging AT and providing rapid evaluation of same.
- Represent MTRR in current and future research projects such as the MTRR evaluation project and the Supportive Memory eBook.

4.9 Funding

Living Well with Dementia is funded by the HSE through FCI. Expenditure per annum on Living Well with Dementia fluctuated between 2018 and 2021, ranging from between €250,000 and €280,000 (Table 4), an average per annum of €269,000. Clinicians highlighted the budgetary constraints under which they are working. They pointed out that their budget had not increased and remained below €280,000 since the first full year that the service started in 2016, making it difficult to meet increasing demand and implement new services developed, thus stifling innovation.

Table 4: Living Well with Dementia in South Tipperary expenditure, 2017-2022

Description	2017 €	2018 €	2019 €	2020 €	2021 €	2022 €
Dementia Support Worker service	122,681	121,505	132,995	130,039	137,991	125,829
Travel Expenses	54,632	51,989	49,459	30,173	41,890	47,700
Salaries NURSE (1.0 WTE) and OT (0.6 WTE) OT MTRR (0.3 WTE) ¹	85,846	82,725	91,410	89,493	91,321 (30,000)	96,220 (30,000)
Miscellaneous	6,680	3,197	4,268	2,579	8,299	8,274
Total Expenditure (excluding OT MTRR role)	269,839	256,219	278,132	252,284	279,501	278,023

Notes

¹ Salaries for 2021 and 2022 include additional funding of approximately €30,000 provided by the NDO through FCI for the engagement of the OT to work part-time (0.4 WTE) providing clinical leadership for the MTRRs Programme. This funding is excluded for the purposes of calculating total expenditure on Living Well with Dementia in 2021 and 2022.

Source: Family Carers Ireland.

4.10 Summary

The four components of Living Well with Dementia combine to create a unique service. The nurse and OT at Living Well with Dementia have multiple roles, and use their knowledge, experience and skills in multiple ways to support people with dementia and their family carers in a very person-centred and individualised way. This happens from the time a person is referred, for person-centred assessments, through to the provision of expert and tailored information, advice and practical supports including a wide range of practical psychosocial interventions. The nurse and OT work directly with service users, immediately or shortly after diagnosis and as the dementia progresses. Their roles also involve frequent liaison with health professionals and organisations. The nurse oversees the DSW Service, while the OT facilitates the MTL.

The nurse and OT roles are distinct but complementary. Throughout, this chapter has given examples of the interdisciplinary way in which the nurse and OT work, a unique feature of the service that enhances the supports offered to people with dementia and their family carers.

Data presented in this chapter show that trends in referrals to Living Well with Dementia have been upwards, as have the average number of people with dementia supported by DSWs, and visits to the MTL. This is not surprising given estimates of an increase in the number of people with dementia in South Tipperary. In addition to increasing prevalence of dementia, the nurse and OT have expanded on the service options available to people with dementia and family carers and increased the availability of psychosocial interventions that are highly valued by people with dementia and family carers. However, the nurse and OT roles, and especially the nurse role, involve a lot of administrative work, which is very time consuming. Without administrative staff, this work falls to the clinicians taking away valuable time they could be spending on work supporting people with dementia and their family

carers. This need for administrative support is becoming more and more pertinent, as demand for services offered by Living Well with Dementia increases. These issues were raised by other stakeholders and are discussed further in Chapter 6.

The Covid-19 pandemic has had a profound impact on people with dementia, but this chapter revealed that following a short initial hiatus, Living Well with Dementia continued to provide supports to people with dementia and family carers throughout 2020 and 2021. It managed to achieve a balance between protecting against Covid-19 and continuing to deliver most of its services and supports throughout the pandemic. Unlike most other services, however, no additional funding was made available to Living Well with Dementia to enable it continue this work. Indeed, despite increasing demand for its services and expansion of the supports it offers, and the contribution it makes to creating resources for use nationally, funding for Living Well with Dementia has not been increased since the first full year of operation in 2016. Increasing demand and limited resources were among the issues and challenges facing Living Well with Dementia that were raised by stakeholders and are returned to in Chapter 6.

The next chapter evaluates Living Well with Dementia and its four main components from the perspectives of people with dementia, family carers, health professionals and other stakeholders who participated in interviews for this study.

Chapter 5: Perspectives on Living Well with Dementia services

5.1 Introduction

Drawing on focus group interviews with staff at Living Well with Dementia and other information available on the service, Chapter 4 provided an overview of the main components of Living Well with Dementia and how they fit together under the umbrella of Living Well with Dementia. This chapter evaluates Living Well with Dementia from the perspectives of people with dementia, family carers, health professionals in South Tipperary and other stakeholders participating in interviews for this study. Seven key themes were identified from the analysis of interview data.

- Good information and referral pathways
- A progressive, unique and highly valued service
- Valued roles of the nurse and OT
- The DSW service as a novel and vital service
- The MTL as an important resource for service users and health professionals
- Complementing other services
- Integrated within South Tipperary

5.2 Good information and referral pathways have been established

In interviews, health professionals spoke about the good information and referral pathways to Living Well with Dementia that had been established. They reported on the efforts they made to inform people with cognitive impairment and dementia and their family carers about Living Well with Dementia by displaying and distributing leaflets to them and telling them about the supports offered. As one health professional stated, whilst holding up the leaflet, “You can see the Living Well with Dementia in South Tipperary brochure which I give to my patients” [SH006]. Another stated:

“The leaflets are freely available here and we would give them out to anybody that either has a cognitive impairment or diagnosed with dementia.” [SH007]

As well as sharing information about Living Well with Dementia, many health professionals including those in the Memory Clinic, the POLL team, the ASI and STUH reported that they regularly refer people with dementia and their family carers to the service. This is consistent with data on sources of referrals presented in Chapter 4. For example, a good pathway has been developed for referrals between the Memory Clinic and Living Well with Dementia. Staff at the Memory Clinic refer all people newly diagnosed with dementia to the service. They also referred people diagnosed with other conditions such as Parkinson’s Disease to the OT at the MTL for information and advice about assistive technology. Health professionals described the referral process as easy and had confidence the service: “Once I refer patients I know they’re looked after.” [SH007]

5.3 A progressive, unique and highly valued service

Health professionals and other stakeholders regarded Living Well with Dementia largely as a progressive service because of its focus on promoting the personhood of people with dementia. They pointed out that Living Well with Dementia is closely aligned with the Irish

National Dementia Strategy (Department of Health, 2014), which has personhood as one of its two overarching principles. They valued the person-centred, individualised approach taken by the staff and that supports provided were carefully planned. They regarded the tailoring of information, advice and supports to each person based on an assessment of the individual's circumstances and needs and the particular context in which they were living as progressive.

"It's very targeted advice that they can provide depending on the context that the person is facing at the time and I really see that." [SH014]

The person-centred approach taken by Living Well with Dementia, they felt, provided a strong antidote to the medicalized environments in which people with dementia often encounter when they attend for appointments in hospitals.

"It takes the medical aspect away in many respects. Hospitals are so medicalised and so busy. But the MTL is not. It's so quiet and people are also given time."
[SH010]

Health professionals regarded Living Well with Dementia as unique because of the combination of services and supports that it offers. They mentioned all four components of the service, and their perspectives on each is reported below in Sections 5.4 to 5.6. For health professionals, the range of practical supports on offer was a unique aspect of the service and a major appeal of Living Well with Dementia. They highlighted the vital importance of having readily accessible post-diagnostic supports available to people newly diagnosed with dementia. A large emphasis was placed on how practical the supports were:

"It provides a huge range of supports for people with dementia, for families and an absolute mine of information for education as well, about anything dementia-related. And yet the support is very practical, very useful for people and it is provided in a very kind of sensitive, thoughtful way." [SH004]

Health professionals regarded the service as being of high quality. They described it as reliable, responsive, and that supports were offered in a timely manner. It was highly valued.

"It is a highly valued service for us [team of five PHNs] and for people with dementia and family carers as well as those waiting to be diagnosed. We would love to see more of it." [SH015]

Participants valued Living Well with Dementia because it was inclusive of people with dementia of all ages, at different stages of the disease progression from people newly diagnosed with dementia through to people at the end of life, and that support was provided over time, which was regarded as essential given that dementia is a progressive condition and that changes are ongoing and often unpredictable. They identified the important role of the service in providing information, advice and support to people with dementia with specific or complex needs such people with younger onset dementia or with challenging behaviours, and that people in different circumstances were supported including those living alone, or where family carers are working.

Some of these health professionals had seen how beneficial supports offered by Living Well with Dementia, especially the DSW service and group programmes, could be for people with younger onset dementia, and gave examples to illustrate. A small number expressed concern that while a greater number of people with younger onset dementia are being identified and receiving a formal diagnosis of dementia, appropriate services for this group are often lacking. They would like to see the kinds of supports offered by Living Well with Dementia available for all people with younger onset dementia across Ireland.

Participants described the supports as ‘a double whammy’ in that they support both the person with dementia and their family carers. This was another highly valued aspect of Living Well with Dementia that health professionals valued, especially the emotional support that is given to family carers.

For some, Living Well with Dementia was valued for the role it plays in reducing stigma associated with dementia, through the individual work that the nurse, OT and DSWs carry out with people with dementia and their family carers as well as through the group programmes. Let’s Talk, the peer support group facilitated by Living Well with Dementia, was given as an example to illustrate the difference that group programmes make:

“So they are people with the diagnosis and they come and maybe share their experiences. For that, as we know, helps to destigmatise it and help cope better with the disease. Collectively when there is support out there to do that people will come and openly share their experiences and remove some of the fear and the stigma associated with dementia.” [SH003]

Health professionals found it reassuring to know that a service like Living Well with Dementia was available to people with dementia and their family carers in their area. Several felt very ‘fortunate’ to have Living Well with Dementia in their area and some argued that this signaled that South Tipperary was highly progressive in its support for people with dementia to live independently at home.

“I think in this local area we have been lucky because we have had this service, that this service isn’t available around the country. It is a unique service.” [SH010]

“My perception of it [Living Well with Dementia in South Tipperary] is that we are very fortunate to have a service like it when we make a dementia diagnosis because it is such a devastating diagnosis. It is good to be able to signpost people onto another service that offers support.” [SH005]

5.4 Valued role of Dementia Nurse Specialist and OT

Chapter 4 showed that nurse and OT have multiple roles. In interviews, health professionals identified the specialist knowledge and skills of the nurse and OT as a key strength of Living Well with Dementia. They highlighted the importance of these roles including with regard to person-centred assessments, care planning and providing expert and tailored information, advice and practical supports.

“Through their experience and trialling different things they can give really, really good nuanced advice, taking the context and various factors that are quite complex to give an answer for. It’s not just a prescriptive service, they really assess holistically what is going on with the person and with the carer and it is very tailored and I think that comes with their experience. Other services might be more blunt in terms of information and advice; we’re just really lucky with all the experience that the people have who work there.” [SH014]

They also emphasised the role that the nurse and OT play in helping people newly diagnosed with dementia come to terms with the diagnosis, informing people about strategies that they could use, and demonstrating a range of assistive technologies available. Family carers also stressed the importance of these roles:

“I have to say that we were gutted with the diagnosis, a lot of sadness, going down a different road and how are we going to manage this and yet we were determined that we wanted him to be cared for at home ... the diagnosis was an awful shock. Whatever we thought we knew about Alzheimer’s, we didn’t. That’s where the nurse and OT really come in to help us.” [Family Carer, FC002]

“I went up to the MTL and in fairness they had everything there. The thing to this day I remember them saying was ‘make sure you put things in place now so that habit will have built in’ before they deteriorate.” [Family carer, FC008]

They noted that the OT at the MTL had built up detailed knowledge through experience and trialling of assistive technologies. They valued the practical strategies and tips offered and the emphasis placed on strengths and enablement.

“They know not to offer somebody a DSW at a time that is not appropriate to the patient or deciding on not giving a piece of tech; for instance.” [SH014]

Family carers stressed the importance of the advice and ongoing support they received from the nurse at Living Well with Dementia and how having the nurse at the end of the phone enabled them to continue in their caring role:

“I would be in contact with the nurses all the time. They are very good. I know they are always there, at the end of the phone when you be in trouble like” [Family carer, FC003].

“... my go to person would be the nurse in Living Well with Dementia and the nurse knows exactly what to say. When I have a bad day, the nurse is there. The journey will come with the acceptance of the diagnosis, but that is where Living Well with Dementia is really good on that side of things or on specific equipment” [Family carer, FC002]

“I don’t know how many times I range the DNS crying saying ‘I don’t know if I am doing the right thing. Am I doing more damage?’ and she would straighten my head out on it and we would go forward ... I don’t know how you would do it without Living Well with Dementia. You couldn’t keep the person at home because no matter how much you

read, everyone's circumstances are different ... and you just need somebody to chat to. There were days and I can still remember myself sitting on the step in the office talking to the DNS with my head in my hands ...' [Family carer, FC008].

Health professionals identified flexibility of the DSW service as another aspect of the model.

"Other services offering support from different areas it can feel a bit disjointed but with Living Well with Dementia in South Tipperary when they have a person in mind they may be thinking: 'OK now they don't need a DSW' but they have that option in mind when things at home are settled, when their circumstance changes, they could benefit, so I think when things get put in the right order at the right time in a more coordinated way ..." [SH014]

Health professionals stressed how important the nurse and OT were as a resource for health professionals in a wide range of services in South Tipperary and beyond. For example, the nurse was identified as a valuable resource for PHNs who get a lot of referrals of people with dementia for public health nursing from GPs, memory clinics, and other services. PHNs, it was pointed out, are generalists and don't have specialist knowledge of dementia. They are often unable to give the time that people with dementia and their family carers need and deserve. They may not be able to answer the challenging questions that people with dementia and their family members ask. For these reasons, having the nurse in Living Well with Dementia who can give people with dementia and their family carers time, have the specialist knowledge to answer any questions that they have and who know the services available is a really important resource for PHNs. Health professionals also benefited from the experience and advice of the OT.

Health professionals identified the interdisciplinary working between the nurse and OT as a valuable aspect of Living Well with Dementia, and important for the informational and educational work they do with individuals and groups, especially in the context of the amount of information and advice that people with dementia and their family carers need to take in following a diagnosis and as the condition progresses. They gave examples of how the interdisciplinary work of the nurse and OT also support health professionals. One example related to joint input by the nurse and OT to health professionals about improving the environment for people with dementia in residential and hospital settings in South Tipperary.

"We were looking to make the ward [in an Approved Centre] more dementia friendly. Better for orientation and way marking. I could come up with a plan, run it by Living Well with Dementia in South Tipperary and they came to have a look and advise, to validate or make changes kind of a thing. I know Living Well with Dementia in South Tipperary do that in the hospitals as well". [SHO14]

5.5 The DSW service is a novel and vital service with benefits for service users and their family carers

All health professionals participating in interviews for this study talked about the DSW service, referring to it as a novel approach and a strength of Living Well with Dementia:

“The big advantage I would see for the person themselves is the DSW. I would love it if we had something similar for the rest of our patients; depression, schizophrenia ... but there is nothing equivalent [for these patients] [benefits of assistive technology] [SH004]

Health professionals described the role of the DSW as supporting the person with dementia by helping the person with activities of their choosing that give them meaning and satisfaction, indicating good knowledge of this service. Based on what people with dementia had told them and their interactions with DSWs, health professionals gave lots of examples of such activities including baking, going for a coffee or fish and chips, going for a walk around town or on the farm, and attending Mass or the hairdressers. Health professionals liked that a DSW was paired with a person with dementia with similar interests, that a personal relationship developed between the person and the DSW and that the person could be supported outside the home and within their community, which they felt was very novel.

Health professionals regarded DSWs as excellent and very committed to their work. Most health professionals were aware that DSWs had training in dementia care, although one health professional thought they might be unpaid volunteers. One of the many positive aspects of the DSW service that health professionals identified was the knowledge and understanding that DSWs had of dementia, their recognition that dementia affects every individual in a unique way, and the way in which they respond in a person-centred, individualised and empathetic way.

“Certainly the feedback I get on the DSW is that they understand the ‘lived experience’ of someone with dementia and DSWs demonstrate empathy towards that. They see that person as a unique person. We take the idea of ‘personhood’ from Tom Kitwood; a unique person with their own individual needs and the DSW has a level of training and understanding in that area of dementia, where that person who is going through an individual journey needs tailored care and support to adapt to their disability.” [SH003]

Health professionals explained that they receive positive feedback on a regular basis from people with dementia whom they refer to the DSW service. In practice, they had observed that DSWs were making a difference to the lives of people with dementia and there were benefits for their family carers as well. They regarded it as particularly beneficial for people with dementia who had low self-esteem or were feeling socially isolated and for family carers experiencing stress and social isolation. According to health professionals, people with dementia had reported back to them that DSWs makes them feel valued. Health professionals perceived there to be a wide range of benefits for people with dementia including improved self-esteem, increased confidence, improved mood, better quality of life and overall wellbeing, maintenance of social skills, connection to the community, feeling less stigmatised, fears about dementia being allayed, apathy reduced and lack of motivation associated with dementia addressed. There was also a perception that DSWs could help people to stay at home for longer. They believed that the friendships people with dementia developed with DSWs were beneficial and it was not having to rely solely on family members:

“I am thinking of another lady ... she was not doing so well, coping with her dementia diagnosis. She needed some support at home ... She got a referral to the Living Well with Dementia program and a DSW put in place. One thing she suffers from is apathy and a lack of motivation, symptoms that can often arise with dementia. So where she sees the value is ‘that person [the DSW] helps to motivate me to improve my stamina for going out for a walk’. [SH003]

For family carers, the perceived benefits identified by health professionals were knowing that there was a fixed time each week enabling them to plan a chore or activity in advance or to take a short break from caring, whilst knowing that the person is doing something enjoyable. This in turn was believed to alleviate caregiver stress. Family carers reported that they benefitted greatly from the DSW services. One family carer remarked that: “It was like an angel standing on the doorstep the day he [DSW] came” [Family carer, FC004]. As well as the time it allows for chores, family carers reported that other main benefits were the peace of mind it gives and the opportunity it provides for self-care:

It [DSW] was a real life-line. I couldn't even put a value on it. It is beyond value. It is hard to quantify because it is the knowledge that you know ten o'clock, ten o'clock somebody is coming. It keeps me going especially as [name of person with dementia] had no [residential] respite” [Family carer, FC004]

“I knew I had [name of DSW] from 10-1 so I had the morning and I had a few jobs to do and made a few phone calls. I was able to go into the PHN in Cashel to collect pads, took the dog for a walk, the OT rang and I was able to talk to her and then finished my walk. It was lovely, it was a beautiful day and I just had kind of freedom and I didn't feel one bit guilty” [Family carers, FC002].

“I work part-time, and Tuesday when I go to work I have an easy mind because I know DSW is here” [Family care, FC002]

“I wouldn't always have headspace or mind space to sit down and think about something and I knew [when DSW is here] I could go in there and sit down at the desk and work things out because the paperwork that is attached to all this is amazing and I couldn't even begin to tell you” [Family carer, FC004]

Health professionals regarded the psycho-educational role that DSWs play (providing tips, suggesting strategies, educating family carers about responsive behaviours) as an added benefit, as well as their roles in developing relationships and bonds and reducing isolation and identifying unmet needs.

All (but one) health professionals rated the DSW service as extremely highly. The exception was a health professional, a primary care professional, who lacked knowledge about the DSW service as indicated by the description of it as a ‘sitting service’, which it seems coloured the health professional's perception of the DSW service. Mostly, health professionals regarded DSWs as a ‘vital resource’ and ‘the most practical aspect of Living Well with Dementia in South Tipperary’. It was referred to by two health professionals as a ‘gold standard’.

“For me that is a ‘gold standard’ ... in my mind this ‘gold standard’ would be applied, as an option for everybody [in Ireland].” [SH010]

“I love the model of the DSW. It’s really valuable and it would be great to be able to roll that out further.” [SH010]

5.6 The MTL is an important resource for services users and health professionals

People with dementia and family carers found the MTL and the assistive technologies there to be useful:

“I met the OT there [at MTL] and it was great to see all the things that we don’t know anything about really until we need them. I found it very good. I got the clock and an awful lot of people admire the clock and it is great, the red, white and blue, it is so clear and a perfect size and you have everything on it. The date and time. It is great. A lot of people admire it. It is great. One look and you are not wondering.” [Person with dementia, P003]

Health professionals liked the concept of the MTL very much and were very proud that the first MTL in the country had been established in their area: “The Memory Technology Library is also a fantastic part of the service that they run” [SH004]. They considered the MTL to be a very practical and solution-focused addition to dementia support services in South Tipperary. Many had visited the MTL on the grounds of STUH to see the rooms for themselves and it had made a deep impression on them. They commented on the good layout of the rooms in the MTL, demonstrating AT that can be used in different rooms of the home. They found the rooms to be well stocked with a wide range of assistive technology devices including sensor alarms, medication organisers orientation clocks, touch button radio, TV remote controls, different types of alarms, and reminders that could enable the person to remain independent, stay well or help keep them safe. They liked that the rooms also displayed a large number of items for helping to engage, stimulate and occupy the person with dementia such as sensory boxes and rummage boxes.

Although the MTL could be accessed by people with mild cognitive impairment or cognitive impairment but no dementia, some health professionals felt that this group of people did not typically access Living Well with Dementia and this could be expanded and supports for them enhanced. Most health professionals felt that people with dementia and their family carers were highly receptive to the MTL and AT and reported that feedback they received from people with dementia and family carers whom they had referred to the MTL had been positive. They gave lots of examples.

“I will always remember seeing a gentleman who was living alone and short term memory was a problem and he was using the orientation clock at that time. He was pointing to it when I was there in the kitchen and saying ‘I would be lost without that. It helps me every day to know the time of day, the date and what’s happening’. And that’s a very basic example.” [SH003]

Health professionals identified a range of benefits of the MTL for people with dementia and they often referred other groups of people as well including people with mild cognitive

impairment and Parkinson's disease. They expected that people visiting the MTL benefited from seeing the equipment themselves, as they had benefitted.

"I could be telling families all kinds of things but if you actually go in [to MTL] and can see it [AT] – you can then visualise it in your own house and think 'I can do that, I can do that'. So it's very practical. It's brilliant." [SH007]

They felt that the MTL promoted awareness among people with dementia and their family carers of the potential of AT and encouraged them to think about how it might be useful to them. The OT was able to advise people with dementia and their family about strategies they could use to help people with dementia live more independently. They saw that every visit to the MTL provided an opportunity for the OT to better inform and educate people about dementia generally and if needed to reframe their thinking and perspectives about dementia and provide them with a better understanding of dementia.

Health professionals reported that the MTL was an important resource for them. Demonstrations by the OT of different assistive technologies enhanced health professionals' knowledge and understanding of how AT could support people with dementia and other groups of people, thereby upskilling health professionals. Through the MTL, health professionals had become aware that there was AT to support people at every stage of dementia, and that often simple, low cost solutions were effectiveness for supporting a person with dementia such as use of labels, colour, and colour contrast.

The use of the MTL as a venue for delivering group programmes such as the Memory Rehabilitation programme was identified as an another important aspect and beneficial for programme participants.

5.7 Complementing other services

A range of other services supporting people with dementia are operating in South Tipperary including Le Cairde, the ASI dementia-specific day care service, and HSE Home Support services, and health professionals referred to these in interviews. Most health professionals were of the view that, far from duplicating other services, Living Well with Dementia was filling an important gap in service provision and complemented other services. They gave many examples to illustrate this.

Like DSWs, health professionals distinguished between the DSW and Home Support service. They pointed out that Home Support services play an important role in supporting people with dementia who need help with personal care. However, Home Support does not cater for those who have no or few difficulties with activities of daily living, but may need support to live well, and to continue their own preferred and usual roles, occupation and interests and be better integrated into the community. Health professionals believed the latter was a vital service for people in need of support with basic activities of daily living but rather restrictive in nature with its sole focus on personal care. The DSW service fills an important gap in this regard. Family carers explained that visits from home care assistants for personal care were so busy and so short that it gives no time for family carers to take even a short break, another important gap filled by the DSW:

“The DSW is a necessary service because the HSE [home care assistants] their feet don’t touch the ground because they are so run off their feet with the three visits in the morning, lunch time and evening. He needs that now for personal care ... My daughter works and has three children so I like to give her the weekend so that is why I don’t call her unless it is absolutely necessary. That is why when the DSW comes on a Monday, it meant if I needed a sleep, if I needed to go in and have a shower and wash my hair and that because I hadn’t been able to all weekend and to feel human again. I never appreciated that until I had to do that. It is the little things, like sitting down with a cup of coffee and just chilling ... I couldn’t speak highly enough of it.” [Family carer, FC004].

Health professionals believed that the DSW service offered a valuable alternative option to day care. Not everyone liked attending day care, it was unsuitable for others and had limitations in that it is harder to provide individualised support in a group setting. Similarly to DSWs, they were keen that the DSW service were not seen as a substitute for other services such as Home Support or day care, but that it could be provided as another support option, and where required, could be provided as an additional support to Home Support and/or day care.

The ASI Dementia Advisor for South Tipperary offers information and advice to people with memory problems or concerns about their memory, both before and after a dementia diagnosis. This service and Living Well with Dementia complement each other. For example, after an initial meeting for information and advice, the Dementia Advisor can refer people with dementia needing further support with information and advice to Memory Rehabilitation Group facilitated by Living Well with Dementia.

“So I could see that this [Living Well with Dementia in South Tipperary] was a service I could refer into especially for the group programmes. I could see how their six week [Memory Rehabilitation] sessions would be great to embed the information properly and to build peoples’ confidence and also to see others like them in the same situation” [SH010]

5.8 Integrated within South Tipperary

Health professionals regarded Living Well with Dementia as well integrated with other dementia care services in South Tipperary. Most of the health professionals interviewed including consultants, nurses and allied health professionals working in the POLL team and at the Memory Clinic referred to the long-standing links they and/or their services had with the Living Well with Dementia since it originated in 2012. They had very good knowledge of Living Well with Dementia, which had been built up over a decade of working closely and building relationships with its staff. Some had been involved in 5 Steps to Living Well with Dementia, from which Living Well with Dementia originated. PHNs too have built up knowledge of Living Well with Dementia over the past decade, helped by the meetings arranged by Living Well with Dementia to inform them about the service. Other health professionals had been briefed about Living Well with Dementia as they took on new dementia-related roles in South Tipperary such as the ASI Dementia Advisor or ANP working with older people in STUH, following which they had met with and developed or were developing links with Living Well with Dementia. The GP interviewed had become more

aware, interested, and knowledgeable about Living Well with Dementia after participating in a dementia training programme for GPs. However, health professionals in primary care indicated in interviews that there were some gaps in their understanding and knowledge about Living Well with Dementia including some misunderstandings about the DSWs and their role. Concern was expressed by some health professionals that in general GPs in South Tipperary lacked knowledge about Living Well with Dementia and OTs in primary care teams didn't engage with the service much.

The close working relationship that many health professionals, including those on the POLL team, had with Living Well with Dementia was another indication of the degree to which the service is integrated. Health professionals spoke about the value of working directly with staff in Living Well with Dementia to support clients with dementia.

“When we need services to rely on, they [Living Well with Dementia in South Tipperary] are there for us; we work with them on a daily, weekly basis really ...”
[SH003]

Shared working was valued by health professionals working in and across primary and community-based services and acute hospital service in South Tipperary. Managerial staff were generally of the view that the Living Well with Dementia provides an essential service to people with dementia and their family carers, is very well integrated with HSE services and many HSE services rely on the service and regularly refer people with dementia to it.

Chapter 6: Demand, staffing, funding, organisational and other issues

Chapter 5 showed that Living Well with Dementia was evaluated very positively by people with dementia, family carers and health professionals and most other stakeholders. It is regarded as a progressive and unique service, as a valuable addition to the dementia care landscape in South Tipperary. It complements other services, is well integrated into the service landscape and acts as an important resource for other health professionals and services. However, study participants identified a range of issues and challenges facing Living Well with Dementia that have implications for service development and sustainability. The issues raised related to demand, staffing issues, funding, geographical issues, organisational issues and positioning of Living Well with Dementia and issues related to the premises and co-location. These are discussed below.

6.1 Demand is high and expected to increase further in future

Service activity data from Living Well with Dementia presented in Chapter 4 show that there has been an upward trend with respect to the number of referrals of people to Living Well with Dementia, the average number of service users supported by a DSW and number of visits to the MTL. Several health professionals in South Tipperary reported noticing an increase in the number of cases of dementia enrolled onto their own services and that more and more of their service users were in need of Living Well with Dementia services. They attributed the increasing demand to four main factors: the growing prevalence of dementia commensurate with population ageing; more people seeking help with memory problems as awareness and understanding of dementia among the public grows and dementia is perceived as less stigmatizing due to public awareness campaigns such as Understand Together; more people receiving a formal diagnosis of dementia than in the past; and that people with dementia were more likely to receive a diagnosis at an earlier stage in the disease progression than previously. These changes were also linked to greater awareness and knowledge of dementia among health professionals and the development of memory clinic and other dementia diagnostic services.

“Just asking them [in-patients in acute hospitals] the right questions. By doing that we are identifying more patients that require memory clinic follow up that then subsequently are being diagnosed with dementia when you follow it up. So there's just more referrals coming into the memory services. There are more patients being diagnosed.” [SH007]

Several health professionals reported referring people with dementia in ever greater numbers to Living Well with Dementia. They were aware that Living Well with Dementia has become busier and had noticed delays in accessing the service.

“The [Living Well with Dementia in South Tipperary] service is being saturated and they don't have enough ... support workers. I don't think they have enough dementia nurse specialists, OTs. So I can imagine, it's really on a shoe string.” [SH007]

The growth in the number of people with dementia in South Tipperary was highlighted in Section 3.3. Stakeholders pointed out that the demand for Living Well with Dementia supports would only increase further in the future due to population growth and population

ageing. The current investment that is being made in dementia diagnostic services would likely lead to a greater proportion of people with dementia with a formal diagnosis, heightening dementia for post-diagnostic supports. There was also a view that as people are living longer, living with dementia is becoming more complex. They highlighted the implications of increasing demand for staffing and funding at Living Well with Dementia.

A recurring theme in interviews with people with dementia and family carers was how grateful they were for the DSW hours they received. Apart from one person, all those interviewed would like to get more support, but were aware that resources were limiting:

“More days, but 3 days is 100%. If someone could come in more days, you would take it, but it is not always there.” [Family carer, FC003]

6.2 Staffing levels are inadequate

Given the increased demand, health professionals argued that Living Well with Dementia was under-resourced in terms of staffing. They did not think that staffing with one WTE nurse and a part-time OT was sufficient to run the service. Other stakeholders believed that it was time for the HSE to review the staffing levels needed for Living Well with Dementia. It was argued that Living Well with Dementia would benefit greatly from the appointment of a full-time service coordinator, possibly with a clinical background, to take on the managerial role that is currently being provided by FCI. Administrative support would also be needed to take on time-consuming administrative tasks currently undertaken by the nurse and OT (e.g., managing referrals and waiting lists) and to support the recruitment and allocation of DSWs.

A key staffing issue raised was the likelihood that at some time in the future the nurse and/or OT may retire or move on to another position, leaving these roles vacant. Participants highlighted the need for succession planning within Living Well with Dementia, as well as a strategy for recruitment and retention.

Another issue raised in interviews was the shortages of and demands on health professionals in other services, such as PHNs, particularly since the onset of the pandemic, which had knock-on implications for Living Well with Dementia and the provision of post-diagnostic supports for people with dementia.

6.3 The contribution of DSWs need to be better recognised and valued

DSWs strongly believed in the value of Living Well with Dementia and their work and described it as rewarding. They enjoyed helping people with dementia and their families. They enjoyed chatting to them and liked the connection and relationships they had with people they supported. However, it also had its challenges. Supporting people with dementia and their family carers, DSWs found, was often emotionally demanding. Leaving work behind could be difficult, and they talked about the strategies they used to unwind at the end of the day. In addition, they often worried about people they have visited, especially if a person with dementia was themselves worried or distressed or a family carer was not coping well. They went above and beyond their duty. At times DSWs had phoned later in the day to check that the person was managing. One DSW has offered support on Saturdays on a voluntary basis to family carers seen to be under extreme pressure and who had no other support available to them. DSWs argued that the supports people with dementia are getting

are often inadequate. They would like to see an expansion of supports so that people with dementia could get a longer visit from a DSW or more than one or two hours a week.

“We can help the client if we are given more time with them. We go to clients for an hour, an hour and a half, two hours only a week, which is not good enough and for us to see them and be sure that they are ok as well. They definitely need to see you more. Sometimes we are the only people that they see.” [DSW005]

Health professionals would like to see more DSWs employed, but supposed that Living Well with Dementia, like other health and social care services, was facing constant and ongoing challenges recruiting, training and retaining DSWs. They attributed this in part to the low value placed on care work and the low wages and difficult working conditions experienced by DSWs, mirroring the points raised by DSWs as reported below.

“[DSWs] are not valued financially and the terms and conditions and contracts under which they have to work suggests that they are not valued. Yet, they have an extremely important role to play in their direct work with people with dementia and family carers. They are important for the person, building relationships with them and have an important monitoring role.” [SH015]

DSWs spoke about the support they get from the nurses in Living Well with Dementia and the high regard they have for them:

“They need to be complimented. They are fantastic. You pick up the phone and they are so nice to you.” [DSW005]

“They are fantastic. They trust us. They are a dream really, that is what keeps me going.” [DSW004]

However, DSWs report their working terms and conditions to be challenging. Because of the size of South Tipperary, providing support to people in their homes could sometimes necessitate DSWs travelling long distances. DSWs identified this as a challenge. Journeys, although not always at a long distance, could be up to 25km from their home. As DSWs pointed out, they don't get paid for travelling time to and from clients, nor do they get paid mileage for the first or last journey of the day. Poor road conditions in remote rural areas affected their car's performance, leading to costs for servicing their cars. They are low paid and the expectation that they would bear that costs of their travel time from their wages was, according to DSWs, an indication of the low value placed on DSWs' work. They believed that the Revenue rule whereby mileage rates reduce once a DSW had accumulated 5,500 km was unfair. Their hours were not always guaranteed, and may be reduced when a client is in respite or admitted to hospital, meaning a reduction in their weekly pay. They reported that all of this could cause stress, especially in the context of increased costs of fuel and rising costs of living. The many changes to policies and procedures arising from the restructuring of FCI had resulted in much more administrative work for them, adding another level of stress, and they felt undervalued by the way they changes had been brought in. Some DSWs had decided to leave FCI and take up a position as carer with other organisations as a result of these changes.

6.4 Living Well with Dementia offers value for money, but is operating under budgetary constraints

Chapter 4 showed that the annual budget for Living Well with Dementia had remained the same since 2016, despite the increase in demand and expansion of supports offered. Clinicians reported finding it hard to meet service demands within the budgetary constraints.

Despite most people with dementia and their family carers receiving very low levels of support, Living Well with Dementia at times were forced to withdraw or reduce the hours allocated due to budgetary constraints. One person with dementia described the negative impact of a temporary withdrawal of the DSW:

“The DSW comes to see me every week for an hour. It used to be an hour and a half but they decreased it to an hour. They said they might get it back to an hour and a half. That is one area that I really benefit, really because when they finished with me at the beginning of August [2022] I was really lost. I felt my whole world was falling in because she was bringing me to town to do my messages and I could go the chemist and to the butcher and another day we would go for a walk. She is back now since last Monday. For the moment it is one hour and they might bring it up to an hour and a half” [Person with dementia, P003]

Asked later in the interview if there were any changes needed, this person stated:

“The hours are scarce because of resources, is that right? If there were more hours. What I am getting like with DSW is very good ... it stopped for a while at the beginning of August until last Monday ... it really brought me down and I looked forward to DSW and deciding what we were going to do whether it was going to town or out for a walk. It would definitely bring me down if it was taken from me. It is important for my well-being. ‘Twas one thing I found fantastic” [Person with dementia, P003].

Stakeholders were aware that there were issues in relation to the funding of Living Well with Dementia, which they hoped would be resolved. They expressed concern about the level of funding and that Living Well with Dementia did not have the resources to meet the growing demand for their supports, meaning that the needs of people with dementia were left unmet, whilst placed on a waitlist for Living Well with Dementia supports. Despite the waitlists, health professionals continued to refer service users to Living Well with Dementia because it offered much needed supports not available elsewhere in South Tipperary.

“We would have got feedback this year that the Living Well with Dementia in South Tipperary program was finding it difficult to sustain aspects of its service because of an increasing number of referrals against maybe having those resources to meet that need. And they were notifying us of that. We still continue to refer because we feel that the service is there; it’s coming from a need that we cannot fulfil.” [SH003]

Stakeholders believed there was a strong case for increasing the funding for Living Well with Dementia because of the demand and because it offers good value for money. Health professions commented on the low level of support offered by the DSW, with people with

dementia typically allocated one or two hours a week. They remarked on how surprised they were to see how much difference such a low level of support can make. They also pointed to the potential cost savings through avoidance or postponement of long-stay residential care:

“A relatively small input, you know once a week it surprises me how much of a difference it makes to for example, keeping people at home, helping carers to cope with behavioural and psychological symptoms. You know it’s much more than just an hour in the week.” [SH004]

“My gut feeling is that no matter what costs are involved, it is still cheaper than putting someone in a nursing home. Any nursing home in Tipperary the minimum is €1,000. I am always arguing if government policy is to keep the person at home this project is one sure way of doing it, because you have proven it already. It is the [caregiver] burnout really. Most carers who ring in here, their nerves are frayed and they are on the last lap and if they get those couple of hours they will definitely keep them at home longer. If their hours are cut even a small amount of hours it can mean them throwing in the towel months and months before you need to.” [SH011]

In some services, health professionals explained that Living Well with Dementia enabled them to discharge people with dementia from their own service. For example, people with dementia who no longer need to be in the care of the POLL team can be referred to Living Well with Dementia where the nurse can act as a point of contact for information and ongoing support and where the person can avail of more appropriate supports such as a DSW than could be offered by the POLL team. This frees up resources in the POLL service for other people in need of community-based psychiatric services. A health professional in an acute hospital stressed that an important part of her role and that of her colleagues was ensuring that people with dementia have appropriate supports in place upon discharge from hospital:

“I suppose it [LWwD] is great for us in a lot of ways as health professionals because you’re not left feeling, you know, people are distressed and might be needing support and advice and you know you can pass them on to the right service and they will get a timely response rather than us not being quite the right service for them; it’s great for our clients.” [SH014]

“We really value it highly and would miss it if it was reduced in any way; that would have a hugely negative knock-on effect for everybody on our team.” [SH014]

In support of their arguments for increased funding for Living Well with Dementia, stakeholders pointed to the available research evidence. The added value of Living Well with Dementia has been well documented (O’Shea and Murphy, 2014; O’Shea and Monaghan, 2015). There is qualitative evidence that the range of supports offered in South Tipperary can delay the need for long-term care for people with dementia and improved their overall quality of life (Cahill et al., 2014). The results of an economic evaluation of the HSE & Genio Dementia Programme suggest that:

‘a significant number of people with dementia could potentially be supported to live at home for longer as a result of the HSE & Genio Dementia Programme, thus resulting

in savings to the exchequer when comparisons are made between public expenditure in the community and in residential care' (O'Shea and Monaghan, 2016).

The evaluation concluded that: 'investment in personalised supports for people with dementia is good value for money for the HSE, especially for people on the boundary between community and residential care' (O'Shea and Monaghan, 2016).

Cullen and Keogh (2018) have also demonstrated there is a compelling value case for the provision of personalised and person-centred supports through community based supports such as those provided by Living Well with Dementia. They concluded that 'the incremental costs, over and above standard care, are relatively small and represent good value for money in delivering on dementia policy and the National Dementia Strategy.'

One health professional identified the Enhanced Community Care Programme as a potential source of funding, given how closely Living Well with Dementia is aligned with Sláintecare and its role in implementing the vision of Sláintecare through the provision of post-diagnostic supports that are keeping people with dementia well and living at home.

6.5 Geographical issues

While Living Well with Dementia is located on the grounds of STUH in Clonmel, people with dementia are dispersed across South Tipperary. South Tipperary covers a large area of 2,257 km² and Living Well with Dementia in South Tipperary supports people with dementia in other large towns such as Carrick-on-Suir and Tipperary and smaller towns from Ballingarry in the north-east to Ballyporeen in the south-west. The area has diverse terrain and Living Well with Dementia seeks to support people with dementia living in the many remote rural and mountainous areas of South Tipperary as well as those living in its large and small towns and villages.

The geography of South Tipperary, with its many small towns and remote rural areas, was identified as a challenge for Living Well with Dementia as well as for other health and social care services. Health professionals argued that there were 'blackspots' with respect to dementia care in South Tipperary and bordering areas. Health professionals believed that with their current capacity and resources, it would be very hard for the nurse and OT in Living Well with Dementia to meet the needs of people with dementia across the whole of South Tipperary, especially those in remote rural areas. Health professionals understood that arranging DSWs for people with dementia in towns at a distance from Clonmel and in remote areas of South Tipperary must be extremely challenging for Living Well with Dementia, and were concerned about the potential unmet needs of people with dementia in such areas.

"I know when looking to make a referral for a DSW with a person living in a very remote rural area, who are vulnerable and are at risk for a number of reasons, it's been very hard to get DSWs to go into some of those out of the way places. They don't seem to have them on the books and I don't know if travel is a factor but it's been much easier to place DSWs when people are based in Clonmel or some of the more urban areas. Sometimes it's those people in rural, remote areas who are more needy because they're so far out". [SH014]

Because of the large areas bordering South Tipperary, and because some people are receiving a diagnosis or other support from health professionals and services in bordering counties, health professionals would like to see Living Well with Dementia expanded to be able to meet the needs of all people with dementia both within and beyond South Tipperary.

6.6 Premises and co-location issues

With respect to the building in which Living Well with Dementia and its MTL is located, health professionals and other stakeholders were aware that Living Well with Dementia did not have security of tenure and had no guarantee from South Tipperary University Hospital that the MTL could remain on the site. They expressed deep concern that the premises could be taken over for another use by the hospital at any time. This was regarded as a major threat to Living Well with Dementia and its MTL and if this transpired would be a huge loss to South Tipperary. Stakeholders wanted a permanent home to be found for the MTL in South Tipperary. Some felt that a 'weakness' in South Tipperary was that the Memory Clinic and Living Well with Dementia were located in different towns and believed that it would be beneficial if they were co-located. Increased public funding coming on stream for Memory Assessment Services and Supports could they believed provide an opportune time for this to happen and for Living Well with Dementia to better resourced.

6.7 Organisation and positioning of Living Well with Dementia in South Tipperary

While Living Well with Dementia is funded by HSE, it is currently managed by FCI through a grant aid agreement with the HSE, under Section 39 of the Health Act, 2004. Grant aid agreements have been in place between the HSE and FCI since October 2015 and are the mechanism through which funded is channeled to Living Well with Dementia. In this way, FCI's involvement has facilitated the continuation of Living Well with Dementia to date. As stakeholders pointed out, Living Well with Dementia 'does not function as part of the HSE'. Being funding through and facilitated by FCI was seen as an advantage by clinicians in Living Well with Dementia and other stakeholders, as it allowed Living Well with Dementia have some autonomy over its service and allowed it to provide a flexible and responsive service to people with dementia and family carers.

The success of Living Well with Dementia was also attributed to close working and trusting relationships at local level between local managers in the HSE and FCI who were highly committed and had been involved in the project from the beginning. The local managers worked to build a strong trusting relationship with each other and with staff in Living Well with Dementia, held regular meetings, and worked effectively together to resolve any issues that arose.

"... the success of it in the first place was the local input, because of the local HSE manager and [local FCI manager] worked very closely together and there was a lot of trust there and [they] knew where it was going." [SH011]

In 2022, there were two organizational changes that affected Living Well with Dementia. These changes and their impacts on Living Well with Dementia were explored in interviews with staff and relevant stakeholders and are discussed further below.

The first was managerial change in the HSE, with the replacement of the Local Manager for Older Person's Services. The new Manager was new to the area and had little prior knowledge of and no history with Living Well with Dementia, which was one of 79 Section 39 funded services under the Local Manager's remit in 2022.

The second was restructuring, growth and managerial change in FCI. In 2022, FCI was restructured into two divisions – Supports and Services. Living Well with Dementia was placed within the new Services division which brought with it a change in management. Local management ceased. Management and decision-making were concentrated at FCI's national office in Tullamore. This led to a less hands-on approach from FCI, much fewer meetings and a weakening of relationships between FCI, the HSE and Living Well with Dementia. Responsibility for recruitment of DSWs also moved from the FCI local branch to the national office, which was seen by some stakeholders as problematic because of the need to have a local understanding of the geography of South Tipperary and distances DSWs have to travel. An emphasis was placed in FCI on bringing DSWs more in line with FCI policies and procedures for its respite home workers. FCI pointed out that DSWs were qualitatively different from FCI's respite home workers with respect to the care they provide, and their terms and conditions, which appeared to be a concern. Under its grant aid agreement, FCI must meet numerous reporting and compliance obligations, and, following restructuring, FCI's focus concentrated more on funding, risk management, contractual issues and ensuring Living Well with Dementia complied fully with FCI systems, policies and procedures. FCI stressed that there was no suggestion that Living Well with Dementia did not have proper policies and procedures in place, only that theirs did not always closely align with FCI's.

“If you have a SLA with the HSE it is literally a list which is several pages long and that list is titled with codes and legislation that you have to comply with and that is a telephone book. We [at FCI] have our ways of doing that and our systems for doing that.” [SH012]

FCI also became more concerned about operational costs to FCI associated with managing Living Well with Dementia such as costs associated with training DSWs and with keeping costs within budget. FCI was concerned that operational costs were not being fully funded by the grant aid from the HSE, which meant that FCI was effectively subsidizing Living Well with Dementia. According to FCI, the burden of management and administration was not sustainable. Funding on an annual basis was also seen to be problematic.

Stakeholders expressed a number of concerns resulting from the above organizational changes. First, stakeholders were concerned that less attention was being paid by the HSE and FCI to building and sustaining relationships. Health professionals believed that strong support from managers in the HSE and FCI was vital to the success of Living Well with Dementia. Second, they were concerned that, with managerial change and organizational restructuring, knowledge and understanding of Living Well with Dementia could potentially be weakened. They argued that new management need to have a good understanding of Living Well with Dementia and of the benefits it brings to South Tipperary. This included an understanding of how and why it originated, the biopsychosocial model that underpins it, the person-centred and individualized approach taken, the role and contribution that it makes to the dementia care landscape both locally and nationally, the high regard with which it is held,

the positive impact that it makes to improving the lives of people with dementia, their family carers and enhancing the work of health professionals in other services.

“You have to have all the stakeholders willing to work together and one not trying to outshine the other. You see, there was none of that in this, but you know sometimes everybody wants the kudos but nobody wants to take the risks. But, they are the challenges of it.” [SH011]

Third, stakeholders expressed concern that FCI seemed to be paying less attention to the needs of people with dementia using the service and their family carers, and to service quality and outcomes. Fourth, concern was expressed that new management did not seem to recognize the role Living Well with Dementia is playing in implementing national policy at a relatively low cost, delivering great value for money and is likely to be cost saving through its contribution to postponement of long-stay residential care as people with dementia are enabled to remain at home longer. They believed that there was sufficient research evidence to support this. There was a more general concern that over time interest in dementia has waned.

The Manager for Older Persons Service was aware of the funding and contractual issues facing Living Well with Dementia, and it is hoped that this report will provide information about Living Well with Dementia, the services it provides, how it fits into the dementia care landscape in South Tipperary and what were the benefits for people with dementia and family carers.

Ultimately, in January 2023, a decision was taken by FCI to withdraw from its involvement with Living Well with Dementia at the end of 2023.

Finding a location for Living Well with Dementia has been an issue since Living Well with Dementia’s pilot phase (O’Shea and Monaghan, 2014). Some stakeholders argued that it was time for Living Well with Dementia to become part of the HSE, which would directly fund and manage it. This could bring advantages, as being part of the HSE could lead to more certainty for Living Well with Dementia and more sustainable funding. A view among stakeholders was that flexibility within FCI, which had been an important catalyst to FCI’s involvement with Living Well with Dementia in the first place, had diminished considerably as the organization had grown.

“Flexible, it has to be flexible. Maybe, every organization is like that as they get bigger, but that is what stifles all of these projects.” [SH011]

There was also a view that the HSE had changed over the last ten years and was better able to accommodate innovative services like Living Well with Dementia without undermining service autonomy and flexibility. A challenge for the HSE is that home care in Ireland is oriented away from being publicly provided to being outsourced mainly to private providers and to a lesser extent non-profit providers (Merceille and O’Neill, 2021). This raises the question of how to best facilitate the continuation of the DSW service, if Living Well with Dementia were to become part of the HSE. This, however is now a moot question, as in mid-2023, a decision was taken by the HSE to bring the OT and MTL under the remit of the HSE. However, there is still a need to find a voluntary sector organization to take over from FCI

and host the nurse and DSW service through another Section 39 grant aid agreement, The responsibility for finding a new host organisation has been placed by the HSE with staff at Living Well with Dementia who are at the time of writing in discussions with a potential host organisation. In any case, now is an opportune time to review the staffing levels and other issues outlined above. Stakeholders argued that the issues facing Living Well with Dementia, including where it is to be positioned and how it is to be funded, staffing levels etc. would best be addressed through meaningful engagement by the HSE with the staff in Living Well with Dementia.

Chapter 7: Discussion and Conclusions

This chapter presents a synthesis of the findings, with a particular focus on drawing together the strengths, challenges, threats and opportunities facing Living Well with Dementia.

7.1 Strengths of Living Well with Dementia in South Tipperary

A large number of strengths were identified by people with dementia, family carers, staff, health professionals and other stakeholders participating in interviews and focus groups (Table A1). Living Well with Dementia was regarded as a valuable addition to the dementia care landscape in South Tipperary. It was seen to be a unique and progressive service, which addresses a gap in dementia care services locally. Participants stressed that rather than duplicating or replacing other services, Living Well with Dementia played a complementary role, illustrating this with examples. Many participants including people with dementia would like to see the model of care extended to other areas of the country. Living Well with Dementia was highly valued by different stakeholders for promoting the personhood of people with dementia, a key principle underpinning the Irish National Dementia Strategy. It was highly valued for providing practical post-diagnostic, psychosocial supports for people with dementia and their family carers in a personalised, individualised and flexible way. A major strength of Living Well with Dementia identified was its specialist, highly qualified and experienced nurse and OT, the interdisciplinary way in which they work, and the roles they play in assessment and care planning, offering specialist information, advice, support and strategies to help people with dementia live independently and engage in daily and meaningful activities as well as to family carers. The ongoing support offered to family carers who find themselves in very challenging circumstances was highlighted. The educational work and role Living Well with Dementia staff play in changing the narrative around dementia and reducing stigma was also highlighted. Health professionals working in other services locally stressed the importance of Living Well with Dementia as a resource for them and pointed out that it freed up resources in their services and provided people with dementia with more appropriate support than they could offer.

Being inclusive of all people with dementia irrespective of age, type or severity of dementia, living circumstances or complexity of need was seen as a strength, as was its dual purpose in supporting both the person with dementia and the family carer. The range of psychosocial supports offered by Living Well with Dementia was identified as a strength. Both the MTL and the DSW service were identified as a strength of Living Well with Dementia and participants spoke at length about the added value of these services. While Living Well with Dementia was seen as a distinct but complementary service, participants stressed how well integrated it was across a number of levels, exemplified by the multidisciplinary nature of the service, its strong linkages and close working with health professionals in other services, referral pathways developed, integration with primary and community care services as well as secondary, acute services and input into long-stay residential care, as well as the links forged between local, regional and national levels. Participants identified a wide range of benefits for people with dementia, family carers and health professionals arising from Living Well with Dementia. The support and funding offered to Living Well with Dementia from the HSE was acknowledged as vital and a major strength. Participants stressed that there was a strong value case for this, because of the wellbeing gains and potential cost savings arising from a relatively low investment by the HSE. The value case was made stronger when the

role that Living Well with Dementia plays in implementing national policy and the contribution that its staff make to the national policy and programmes such as the MTRRs.

7.2 Challenges facing Living Well with Dementia in South Tipperary

Seven main challenges facing Living Well with Dementia were identified by study participants (Table A2). The most immediate of these are managerial changes within the HSE and restructuring within FCI. Within the HSE, the local manager is new to the area and less familiar with Living Well with Dementia. In this context, this research will provide valuable information on how the service operates, outline the benefits it has for people with dementia, family carers and health professionals in the dementia care landscape in South Tipperary and show the value case for its existence. Restructuring within FCI led to a move from Living Well with Dementia being locally to centrally managed, which coincided with an increased focus on costs and risk management, and the implementation of changes to bring the DSW service into close alignment with FCI home respite service. Close working relationships between local managers in the HSE and FCI has been vital to the success of Living Well with Dementia. Managerial change in both organisations led to a less hand-on approach with much fewer meetings. Ultimately, FCI took a decision in January 2023 not to renew the Section 29 grant aid agreement, effectively ending its role in facilitating Living Well with Dementia at the end of 2023. The HSE has since taken a decision to bring the OT and MTL within its remit. At the time of writing discussions are ongoing between the staff at Living Well with Dementia and a potential host organisation. However, while these negotiations continue, the Dementia Nurse Specialist and DSW service remain in limbo and under threat.

A key challenge facing Living Well with Dementia identified by participants was increasing demand. The overall trend in referrals to Living Well with Dementia have been upward, and other health professionals in South Tipperary reported increased demand for support from people with dementia and their family carers for their services too, which is anticipated to increase further in the coming years. Increased demand was attributed to increasing numbers of people with dementia due to population ageing, more people seeking help with memory problems as awareness and understanding of dementia among the public grows and dementia becomes perceived as less stigmatizing; more people receiving a formal diagnosis of dementia than in the past; and move towards diagnosing people with dementia at an earlier stage in the disease progression than had been the case. Given the increasing demand, and reliance of health professionals in other services on Living Well with Dementia, its existence will become increasingly important in the future.

Two key challenges were identified that could potentially be addressed alongside the most immediate issue of finding a location and funding mechanism. These are the staffing levels in Living Well with Dementia and issues in relation to the building in which it is located. The current staffing levels are considered to be inadequate for Living Well with Dementia to effectively meet the demand for its services. Following FCI's decision to cease its role in managing Living Well with Dementia, there is a strong case for appointing a service manager for Living Well with Dementia. There is also a strong case for appointing a part-time clerical officer to provide administrative support to the nurse and OT in relation to managing referrals and appointments, assisting with administrative tasks associated with care assessment and planning, the DSW service and delivery of group programmes. The appointment of a service

manager and administrative support would free up valuable time of the nurse and OT and enable them to concentrate on core aspects of their respective roles.

The location of Living Well with Dementia on the grounds of STUH is considered to be well placed. However, there are issues with the building. The staff working in the service face uncertainty as the building is not guaranteed to Living Well with Dementia and the service is under constant threat of losing the building at short notice. This issue needs to be urgently resolved. A permanent location for Living Well with Dementia needs to be found. Potentially, Living Well with Dementia could remain in its current location under an agreement negotiated with STUH. Such an agreement would need to address upkeep and maintenance issues in the building. There may be benefits in the longer-term from co-location of the Living Well with Dementia in Clonmel with the memory clinic in Cashel.

Staff recruitment and retention is an ongoing challenge, particularly in relation to DSWs, and attrition has been exacerbated by the restructuring within FCI. DSWs were identified by senior staff at Living Well with Dementia, people with dementia and family carers, and health professionals in other services as a major asset of Living Well with Dementia and are seen as a vital component of the service. Their commitment to providing personalised support to persons with dementia, building relationships and enabling them to participate in the community was strongly evident. Any new arrangement for Living Well with Dementia must take account of the DSW service, which may be challenging. There is a likelihood that at some time in the future the Nurse and OT may retire or move on to another position, leaving these roles vacant. Participants highlighted the need for succession planning within Living Well with Dementia, as well as a strategy for recruitment and retention.

The geography of South Tipperary, which covers a large area, with many towns and rural, mountainous and remote areas, is a challenge for Living Well with Dementia as it is for many other services in South Tipperary. Concern was expressed about the needs of people with dementia living at a distance from Clonmel and in remote areas of South Tipperary. A particular challenge is recruiting DSWs from across South Tipperary to match need and reduce travelling distances. The participants believed could be better managed locally, with knowledge of the geography of South Tipperary. The appointment of a service manager and administrative support would greatly help with this issue.

7.3 Threats facing Living Well with Dementia

A number of threats were identified. The biggest threat to Living Well with Dementia has been FCI's decision to cease facilitating the service at the end of 2023. While the OT and MTL are to come under the HSE's remit, there is still the matter of securing a host organisation for the nurse and DSW service. The staff at Living Well with Dementia, who have been tasked with this responsibility and at the time of writing are in negotiations with a potential host organisation, would benefit from ongoing support with this from the HSE. Another serious threat facing Living Well with Dementia is uncertainty regarding the building, and urgent action is needed to negotiate with STUH and secure a longer-term tenancy agreement.

Close working relationships between Living Well with Dementia and the HSE have been vital to the success and continuation of the service to date. Revitalising these close working

relationships will be essential for sustaining Living Well with Dementia into the future. Regular, solution-focused meetings between the HSE and staff in Living Well with Dementia would help this happen.

7.4 Opportunities for Living Well with Dementia in South Tipperary

Despite these challenges and threats, opportunities were identified by participants. The recognition of Living Well with Dementia by the HSE and the invaluable support from the HSE, which has been ongoing from 2012, were identified as a major opportunity for Living Well with Dementia. Living Well with Dementia is a valuable asset for the HSE, because of its contribution to the implementation of the Irish National Dementia Strategy, in particular the priority action areas 'Integrated Services, Supports and Care for People with Dementia and their Carers', but also in relation to the priority actions areas of 'Better Awareness and Understanding' and 'Training and Education'. Living Well with Dementia is helping the HSE achieve the work plan outlined for dementia in its Service Action Plan for 2023 (HSE, 2023b). One of the HSE's key objectives for 2023 is to ensure timely access to dementia care and reduce waiting lists, including through the enhancement of dementia assessment, diagnostic and post-diagnostic support services and enhancing dementia supports through service developments, training, quality and other initiatives.

The health professionals in Living Well with Dementia have collaborated with the NDO, and the strong working relationships with the NDO could be revitalised with the newly appointed Programme Manager and Clinical Lead. These strong relationships could be harnessed in working to put Living Well with Dementia on a firmer footing during its next phase of development. The HSE Model of Dementia Care in Ireland, launched by the Department of Health in May 2023, could provide a potential opportunity for Living Well with Dementia. This is because Living Well with Dementia is so closely aligned with the Model. It embodies the Model's principles, places an emphasis on immediate care planning post-diagnosis, and providing post-diagnostic supports across the Model's five strands. Living Well with Dementia provides an excellent working example of the HSE's Model of Dementia Care in Ireland. As funding comes on stream for the development of additional Memory Assessment and Support Services, this could potentially provide an opportunity for putting Living Well with Dementia on a firmer footing over the long-term.

This study shows that Living Well with Dementia is highly valued and there is a high level of support for Living Well with Dementia locally. It may be an opportune time to bring supporters together into an alliance to work with the HSE towards finding ways of putting Living Well with Dementia on a firmer footing. In its earlier iteration, the Dementia Consortium worked well as an instrument for driving change, and it could be re-established and revitalised with new members. However, given the difficulties in sustaining a Dementia Consortium over a longer period, this would be for a set purpose and a set period of time.

7.5 Conclusions

This study has described the evolution of Living Well with Dementia and identified three distinct phases of development. The first phase 2012-2015 saw the establishment and demonstration of the value of the 5 Steps to Living Well with Dementia in South Tipperary project. In the second phase 2015-2019, Living Well with Dementia was embedded into the infrastructure of South Tipperary and over this period supports on offer were improved upon

and expanded, within resources available to the service. The third phase, 2020-2022 were turbulent years for Living Well with Dementia. Despite the challenges of the Covid-19 pandemic, the service continued to operate most of its services, without additional funding. Managerial change within the HSE and restructuring within FCI in these years have been a key feature of this phase.

Living Well with Dementia provides supports to people with dementia and their family carers through a unique combination of four main components - nurse and OT, DSW service and MTL. These supports are specialist and wide-ranging, covering information, advice, dementia care assessment and planning, practical in-home supports that are personalised, individualised and flexible support. They are provided by a small team of highly qualified, experienced and dedicated multidisciplinary team, supported by trained DSWs. Despite the upward trend in referrals and expansion of supports on offer, funding for Living Well with Dementia has remained constant since 2016.

People with dementia, family carers, health professionals and other stakeholders identified a large number of strengths of Living Well with Dementia. They regard Living Well with Dementia as a valuable addition to the dementia care landscape. They value its work in promoting personhood of people with dementia and the wide range of supports on offer, and that it is inclusive of all people with dementia and serves a dual purpose of supporting both the person with dementia and their family carers. Staff in Living Well with Dementia are regarded as a key strength of the service. The MTL and its leadership by an OT and the Dementia Worker Service were both identified as important aspects of the service. The integration of the services on a number of levels was another strength. Living Well with Dementia is highly regarded by people with dementia, family carers and health professionals. The perceived benefits for people with dementia were wide-ranging. In addition to wellbeing gains identified, the relatively low intensity and cost of supports and potential for cost savings provides a strong case for investing in the service. The value of Living Well with Dementia beyond South Tipperary was recognised by participants. People with dementia, family carers and health professionals were very proud to have an innovative service of such high quality and standing in their locality and would like to see the model extended to other areas.

The study has identified a number of challenges facing Living Well with Dementia, the most pertinent of which has been managerial change within HSE and restructuring within the FCI. Other challenges that need to be strategically planned for are the increasing demands for its supports and other services in the area, and the need to increase staff capacity within Living Well with Dementia to effectively provide supports and meet demand, which will have implications for level of funding invested in the service by the HSE. Increasing the staff capacity will help with addressing issues related to the geography of South Tipperary and enable the service to effectively reach more people across the area. However, longer-term strategic planning in relation to staff recruitment, retention and succession planning is needed. Issues in relation to the building in which Living Well with Dementia is located were also identified as a challenge that needs urgent attention.

Managerial change and FCI's decision to withdraw its role in facilitating and managing the service have been the biggest challenge for Living Well with Dementia recently. While a solution has been found for the OT and MTL, support for Living Well with Dementia must be

mobilised to avert any threat to the nurse and DSW service. Engagement and close working between Living Well with Dementia and the HSE will be required during the process of securing a new host organisation for these two components of Living Well with Dementia. Close working relationships have been vital to the success of Living Well with Dementia to date and are key to its success in the future. The recognition and support that the HSE have given to the service since 2012 has not gone unnoticed and is highly valued by all stakeholders. HSE support is therefore seen as a major opportunity for Living Well with Dementia. However, this must be seen in the context of the contribution that Living Well with Dementia makes to the HSE through its role in implementing national policies and programmes and its close alignment with the HSE's new Model of Dementia Care in Ireland. In this context, there may be opportunities to channel funds to Living Well with Dementia through national level funding aimed at improving memory assessment and support services and develop integrated pathways between diagnostic and post-diagnostic supports.

Recommendations

Recommendation 1: Ensure the immediate sustainability of all four components of Living Well with Dementia in South Tipperary as a matter of urgency

FCI's decision to cease its facilitation of Living Well with Dementia in South Tipperary at the end of 2023 makes sustainability an urgent matter. While the OT and MTL are to come under the HSE's remit, there is still the urgent matter of securing a host organisation for the nurse and DSW service. This is a matter of urgency.

Recommendation 2: Secure a guarantee from South Tipperary University Hospital with respect to Living Well with Dementia in South Tipperary's tenancy in the building in which it is currently located as a matter of urgency

Recommendation 3: Expand the capacity of Living Well with Dementia

It is important to expand the capacity of Living Well with Dementia in South Tipperary for supports to be effectively delivered and to meet the increasing levels of demand for its supports. There is a strong case for appointing a full-time service manager to provide operational management and strategic leadership and a part-time clerical staff member for administrative support.

Recommendation 4: Develop a five-year strategic plan setting out clear goals, priorities and strategies for ensuring the longer-term sustainability of Living Well with Dementia in South Tipperary.

Recommendation 5: Identify a sustainable funding mechanism and develop a multi-annual financial plan for Living Well with Dementia in South Tipperary.

Recommendation 6: Consider re-establishing the Dementia Consortium for a set period to engage with stakeholders including people with dementia and family carers and harness support

Recommendation 7: Ensure a permanent home for Living Well with Dementia in South Tipperary

Recommendation 8: Develop a staff recruitment, retention and succession plan

Recommendation 9: Explore the potential for leveraging funding sources such as funding for development of MASS or funding for implementation of Sláintecare

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Appendix I: Living Well with Dementia in South Tipperary – Strengths, Challenges, Threats and Opportunities

Table A1: Strengths of Living Well with Dementia in South Tipperary

	Strengths	Description
1	A valuable addition to the dementia care landscape in South Tipperary	<ul style="list-style-type: none"> - Unique and progressive model of dementia care - Addresses gaps in dementia care landscape - Complements as opposed to duplicating or replacing other services
2	Promotes personhood of people with dementia	<ul style="list-style-type: none"> - Promotes personhood of people with dementia - Provides personalised, individualised and flexible post-diagnostic, psychosocial supports to people with dementia and their family carers
3	Staffed by highly experienced, qualified Dementia Nurse Specialists and OT	<ul style="list-style-type: none"> - Involved in assessment, care planning for people with dementia post-diagnosis - Provide and arrange post-diagnostic support for people with dementia and family carers - Provide expert information, advice, support, strategies and education - Act as a resource for health professionals in a wide range of services in South Tipperary and beyond
4	Inclusive	<ul style="list-style-type: none"> - Inclusive of people with dementia of all ages and types of dementia, with different complexity of need, different living circumstances, and from before diagnosis to end of life
5	Dual purpose	<ul style="list-style-type: none"> - supports both person with dementia and their family carers
6	Range of psychosocial supports on offer	<ul style="list-style-type: none"> - offers a range of psychosocial supports tailored to the needs and preferences of people with dementia and their family carers - psychosocial supports include both individual and group supports
7	Dementia Support Worker service and Dementia Support Workers	<ul style="list-style-type: none"> - Individualised supports offered engage people with dementia in meaningful activities, building relationships, and participating in community life - Delivered by a committed team of trained and experienced dementia support workers who are highly regarded by service users and health professionals in South Tipperary
8	Memory Technology Library	<ul style="list-style-type: none"> - Facilitation by OT with expertise in dementia care - Trialling of assistive technologies by OT - Demonstration of a wide range of assistive technologies - Expert information, advice and strategies offered to people with dementia and family carers as well as people with other conditions - Loan facility for people with dementia and families to test assistive technology before purchasing - Educational work undertaken - Resource to health professionals - Co-location of OT and nurse

		<ul style="list-style-type: none"> - Model for establishment of Memory Technology Resource Rooms throughout country
9	Integrated on a number of levels	<ul style="list-style-type: none"> - Multidisciplinary team of nurse and OT, working together and with trained dementia support workers - Strong linkages with many services in South Tipperary and referral pathways developed - Horizontally and vertically integrated through close working with health professionals in diagnostic, primary and community care, secondary care and acute hospital care and long-stay residential care services in South Tipperary - Complements rather than duplicates other services - Linkages between local and national level through contribution and collaboration with NDO and national level programmes
10	Highly regarded	<ul style="list-style-type: none"> - Living Well with Dementia is highly respected and valued by people with dementia and their family carers using the service - Health professionals in a wide range of service in South Tipperary have high regard for and confidence in Living Well with Dementia - Held in high esteem by the National Dementia Office
11	Perceived benefits	<ul style="list-style-type: none"> - Well-being gains as evidenced by independent research studies - A wide range of benefits for people with dementia and family carers as reported by service users, staff and health professionals
12	HSE funding	<ul style="list-style-type: none"> - Funding from HSE an acknowledgement of contribution that Living Well with Dementia in South Tipperary contributes to dementia care landscape both locally and nationally - Section 39 funding has facilitated Living Well with Dementia in South Tipperary's flexibility and autonomy
13	Value case and potential for cost savings	<ul style="list-style-type: none"> - Well-being gains support the value case of Living Well with Dementia in South Tipperary - Potential cost savings through avoidance or postponement of long-stay residential care, as evidenced by research and as highlighted by stakeholders - Frees up resources of other health services as reported by health professionals in South Tipperary
14	Implements and contributes to national policy and programmes	<ul style="list-style-type: none"> - Integral to the HSE's MTRR programme - HSE's Post-diagnostic Support Pathway

Table A2: Challenges facing Living Well with Dementia in South Tipperary

	Challenges	Description
1	Organisational change and positioning of Living Well with Dementia in South Tipperary	<ul style="list-style-type: none"> - Managerial change within HSE - Restructuring within FCI leading to move from service being locally to centrally managed, with greater focus on cost containment, risk management and alignment with FCI policies and procedures - Less frequent meetings and much reduced engagement and close working with Living Well with Dementia in South Tipperary
2	Increasing demand, predicted to continue into the future	<p>Due to:</p> <ul style="list-style-type: none"> - increasing number of people with dementia in South Tipperary associated with population ageing - more people living in South Tipperary seeking help with memory problems as awareness and understanding of dementia among the public grows and dementia is perceived as less stigmatizing due to local and national reness campaigns - more people receiving a formal diagnosis of dementia than in the past in South Tipperary - people with dementia in South Tipperary more likely to receive a diagnosis at an earlier stage in the disease progression than previously
3	Staffing levels	<ul style="list-style-type: none"> - Staffing resources - 1 WTE Dementia Nurse Specialist and 0.6 WTE OT - are not sufficient to operate the service and meeting demand - Lack of administrative support for assisting with referrals and DSW service - Loss of service manager for managing operational issues upon withdrawal of FCI in 2023 - Shortages of health professionals, e.g., PHNs, in other services in South Tipperary
	Funding	<ul style="list-style-type: none"> - Insufficient funding levels to meet growing demand - Lack of multi-annual funding and sustainable funding stream
4	Staff recruitment and retention	<ul style="list-style-type: none"> - Recruitment and retention of DSWs an ongoing issue - Experienced and qualified health professionals could potentially retire or move on leaving positions vacant - Exacerbated by organisational changes and uncertain future
5	Building and co-location issues	<ul style="list-style-type: none"> - Use of building not guaranteed by South Tipperary University Hospital
6	Geographical issues	<ul style="list-style-type: none"> - Large geographical area with large number of small towns and remote rural areas makes it difficult to reach people with dementia in all areas of South Tipperary

Table A3: Threats facing Living Well with Dementia in South Tipperary

	Threats	Description
1	Positioning and funding mechanisms	<ul style="list-style-type: none"> - Living Well with Dementia in South Tipperary does not currently function as part of the HSE - In the absence of other suitable resource allocation mechanisms, HSE has relied on Section 39 grant aid agreement to fund Living Well with Dementia in South Tipperary since 2015. - Following FCI's decision to cease facilitating Living Well with Dementia in South Tipperary through Section 39 grant aid agreement with HSE, HSE had decided to bring OT and MTL under its remit. - Urgent need to secure a new host organisation for Dementia Nursing Specialist and Dementia Support Worker Service of Living Well with Dementia in South Tipperary.
2	Building	<ul style="list-style-type: none"> - Permission to use the building could be withdrawn at short notice without another building secured for use
3	Perceived waning of interest or understanding of dementia care	<ul style="list-style-type: none"> - Knowledge and understanding of dementia care and of the role and contribution that Living Well with Dementia in South Tipperary makes to the dementia care landscape may not be well known among staff who have not had direct links to the service - Concern that interest in dementia care can wane over time, highlighting the need for continual awareness raising and promotion

Table A4: Opportunities for Living Well with Dementia in South Tipperary

	Opportunities	Description
1	Support from and relationships with HSE	- Acknowledgement by the HSE of the value of Living Well with Dementia in South Tipperary to the dementia care landscape, both locally and national, which is backed up by ongoing support and resources, and good working relationships
2	National Dementia Strategy	- Living Well with Dementia in South Tipperary is closely aligned with the Irish National Dementia Strategy, and contributes to the implementation of the strategy
3	National Dementia Office	- Staff in Living Well with Dementia in South Tipperary have collaborated with the National Dementia Office and built strong working relationships, which can potentially be revitalised with the recently appointed Programme Manager and Clinical Lead in the National Dementia Office
4	HSE Model of Dementia Care in Ireland	- Living Well with Dementia in South Tipperary closely aligns with the HSE's Model of Dementia Care <ul style="list-style-type: none"> - embodies the six principles as defined in the HSE's Model of Dementia Care – citizenship; person-centred approach; integration; personal outcome focused and timeliness - is undertaking care planning as envisaged in the HSE's Model of Dementia Care; - is providing post-diagnostic supports across each of the five stands identified by the HSE's Model of Dementia Care, i.e., Understanding and planning; Staying connected; Staying healthy; Supporting cognition; Supporting emotional wellbeing. - Living Well with Dementia in South Tipperary offers an excellent example of how the HSE's model of dementia care can work in practice in relation to Care Planning and Immediate Post-diagnostic Support, and the integration of Dementia Post-Diagnostic Support with the Dementia Assessment and Diagnostic Pathway.
5	Future funding for Memory Assessment and Support Services (MASS)	- Further funding being sought by the HSE to fund the development of additional MASS includes funding for uplifting existing memory clinics to become a MASS. Such funding could potentially be used in South Tipperary to put post-diagnostic supports on a firm footing and thereby strengthen diagnostic and post-diagnostic pathways in South Tipperary.
6	Local support and alliances with health professionals and other stakeholders in South Tipperary	- Dementia Consortium, comprising members representing a wide range of stakeholders invested in bringing about change in dementia care in South Tipperary, had in the past been instrumental in driving the service forward can could be re-established and refreshed with new members for a set period of time.
7	Succession planning	- Potential for the development of a strategy to plan for replacement of staff who retire or move on and plan for the passing on of leadership role in Living Well with Dementia in South Tipperary

