



## **Post-Diagnostic Support for People with Dementia and their Carers**

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## Executive Summary

Dementia remains hugely undetected and under-diagnosed in Ireland. Internationally, we know that fewer than half of people with dementia ever receive a formal diagnosis. That figure is likely to be even lower in Ireland. There are also significant delays from symptom onset to diagnosis for people who are eventually diagnosed. Sometimes this is due to the difficulty of differentiating normal ageing from symptoms of dementia; other times it reflects a lack of knowledge about the disease. Case complexity can also make diagnosis difficult even when the person presents for examination. Stigma and fear of the unknown can impact on the decisions of people to seek diagnosis. Therapeutic and resource nihilism can prevent doctors from disclosing a diagnosis, particularly if they believe significant care gaps exist in relation to the disease. There is also support for the view that diagnosis without adequate support is not beneficial and maybe detrimental for people with dementia. Diagnosis in dementia is, therefore, not an endpoint in itself but is just one component of a complex care pathway that has both a past and a future.

There is growing evidence on the importance of a timely diagnosis, including economic benefits. People tend to value certainty over uncertainty and a diagnosis can take some of the anxiety away from the illness, particularly if it is accompanied by information and a coherent care plan. During the early phase of dementia both pharmacological and other interventions such as information, peer supports and counselling, are likely to have maximum effect. Early intervention can also improve patient self-efficacy and enhance dementia symptom management and behavioural changes. Post-diagnostic support provides an opportunity for both practitioners and people with dementia and their carers to work together and set realisable goals for care and support in the early stages of the disease. Early provision of in-home support has also been identified as decreasing the risk of premature institutionalisation; so too have integrated programmes of support for family carers at diagnosis. The importance of post-diagnostic support has also been recognised in Ireland and this

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study was commissioned by the National Dementia Office as part of the post-diagnostic support pathway project.

The main aim of post-diagnostic support services is: to help people with dementia to continue living well in the community; provide information and support; help people to manage issues as a result of getting a diagnosis; and delay admission to long-term residential care. Emerging evidence from psychological sources suggests that the psychosocial potential of people in the early stages of dementia is considerable. Many people are capable of adjusting to a diagnosis and can learn to cope with the implications of the illness for themselves and their family. Additionally, people with dementia appear capable of insight, including being able to evaluate the quality of their own life and of being meaningfully involved in decision making about their own immediate care needs and future choices. Post-diagnostic support is crucial to both contemporary and future decision-making. Post-diagnostic support can help people work through the disease and enable them to plan for a life beyond diagnosis. Information, social contact and peer support can also help to reduce anxiety and isolation following diagnosis. Support following diagnosis is also important for carers of people living with dementia. The problems faced by spouses and partners are amplified by a lack of understanding about the diagnosis and symptoms of dementia. Post-diagnostic interventions can support family members by increasing their knowledge and awareness of dementia. Knowledge of potential care trajectories is also important for carers.

It is difficult to establish a coherent framework that covers all of the potential elements of post diagnostic support for people with dementia and their carers. People who are newly diagnosed with dementia may not know about existing services. Others may know about services, but are unaware of how to access them. Existing services may suit some people more than others. Stigma may be a problem for people in identifying themselves as needing support. Cost may also be a constraint for people in accessing appropriate care. The development of a framework is further

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complicated by the timing of diagnosis. The needs of people diagnosed in the early stages of disease are different to people diagnosed in the later stages of the disease. For the latter, post diagnostic support could mean admission to long-stay care depending on the severity of the symptoms. People in the early stages of the disease may only need information about the disease and signposting to appropriate community-based services. Post diagnostic support is currently focused mainly on supporting people in the early stages of the disease. For example, the NICE-SCIE Guidelines 42 suggest that people with dementia have the right to be fully informed about care, through written information, and to make decisions in partnership with the care team. The Guidelines suggest that people with dementia get information on: the type of dementia, symptoms and on-going development of the disease; treatments; local care services; support groups for dementia; advocacy services; and financial and legal advice. This is much easier to achieve if diagnosis occurs early in the disease.

The Scottish 5-pillar model for post-diagnostic support talks about: understanding the condition and managing symptoms; supporting community connections; peer support; planning for future care; and planning for future decision-making. This model is predicated on people remaining engaged and active with dementia and living well with the disease. It is based on a belief that self-management is possible with dementia provided people are immediately supported post-diagnosis. Keeping people strong and intact following diagnosis is fundamental to this approach. To do this, people must understand the disease, remain physically and mentally well, maintain relationships, keep socially connected, build on their capabilities and have clear signposting and pathways to individualised services and supports. Of course, there will be key transitions along the continuum of the disease, but the first stage is that people are supported to come to terms with the diagnosis and have the information, knowledge and support structures that allow them to make good early decisions that will influence future care trajectories for the better.

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There is a common language of post-diagnostic support across national dementia strategies worldwide. The emphasis is on managing symptoms and maintaining independence, as well as providing support for families and carers through seamless integrated multi-sectoral provision. Information and advice is central to every national dementia strategy, so too is signposting and supporting existing community connections and making new ones. Planning for future needs is also part of international post-diagnostic support programmes. There are different structural approaches across countries in relation to the organisation and delivery of post-diagnostic support. England have dedicated Dementia Advisors; Scotland have Link Workers; while other countries use some combination of support workers, care co-ordinators, case managers or dementia guides to deliver post-diagnostic support. The Irish National Dementia Strategy references *named key workers* within primary care services and *dementia advisors* as potentially having important roles in any future delivery of post-diagnostic support in this country. Having a named key worker is included as a *priority action* in the Strategy to co-ordinate care and continuity, as well as ensuring access to appropriate information and advice. Dementia Advisors are associated in the Strategy with the provision of timely information, signposting and social support. Through an *additional action* in the Strategy, the HSE are mandated to consider the provision of Dementia Advisors in Ireland on the basis of the experience of their effectiveness in demonstrator sites.

While there is lot of activity in regard to post-diagnostic support across many countries, the evidence base with regard to the effectiveness of various interventions is at best ambiguous and at worst weak. Considerable inconsistency between study designs and methods prevents meaningful comparison across studies and undermines the validity of the evidence base. There are few proven and internationally accepted evidenced-based psychosocial interventions for people with early stage dementia living in the community. Although there are many examples of good practice, few interventions have been rigorously evaluated. The majority of supports fall into the category of *potential benefit for people with dementia*, due to

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conflicting results arising from weaknesses in study design. There is, therefore, little evidence to draw clear conclusions from in regard to optimal supports or combinations of support.

Information, advice and peer support are the main sources of post-diagnostic support for people with dementia and their carers. What we know from the literature is that the information provided to people with dementia is often generic and of variable quality. It is often geared to the needs of carers rather than the person with dementia. Existing trials have not succeeded in identifying specificity in relation to the effectiveness of the information provided, so we do not know what type of information works best, for whom, in what circumstances. What is clear though is that people value individualised information, delivered as part of a complex multi-component programme for tackling dementia. There is support in the literature for the role of dementia advisors and peer support networks within post diagnostic support systems, drawn mainly from the Healthbridge project in the UK. Independence, confidence, understanding, community awareness and social networks have all been enhanced through contact with dementia advisors and peer support programmes. There is emerging evidence in support of a tiered approach to information provision, building towards a known, meaningful and sustained relationship between the person with dementia and a named contact. Dementia cafes have also been identified as having the potential to be an important part of peer support for people with dementia and their carers, providing an environment where people can come together in an informal way to receive advice, social support and signposting.

There is trials-based support for cognitive interventions for people recently diagnosed with dementia, especially people with mild to moderate dementia. There is evidence of improvements in communication, social interaction and quality of life. Questions remain as to how long benefits last and there is always the caveat about the quality of the trials and the small sample sizes, but the results are promising. This is reflected in the inclusion of cognitive stimulation therapy (CST) in NICE guidelines

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for the care of people with dementia. CST yielded higher scores on MMSE, ADAS-Cog and QoL-AD instruments than usual care. Improvements in spoken language are an important feature of CST programmes for people with dementia. There is also support in the evaluation literature for conducting CST in small groups. Individual CST is well received by people with dementia and their carers, but the overall evidence on effectiveness is weaker, especially for any potential impact on carers. Cognitive functioning with maintenance CST was further enhanced when combined with early pharmacological interventions, particularly AChELs. The limited cost effectiveness analysis that has been undertaken also supports CST for people with dementia.

There is emerging and consistent evidence to suggest that participating in psycho-educational interventions, incorporating skills training, peer support programmes, psychological therapies and counselling, has positive effects on caregivers of people with dementia. The National Collaborating Centre for Mental Health's (2007) review of qualitative evidence suggested that psycho-educational interventions can be effective in reducing the risk of depression and bolstering coping skills amongst carers if offered early in the dementia trajectory. The benefits of psycho-educational interventions are strongest where: the carer attends a separate group to that of their relative; support is tailored to the needs of a specific group of carers at a particular stage of caring; the intervention includes a combination of skill building, education and support; and it is easily accessible, low cost and time limited. While the quality of the evidence remains an issue, it is reasonable to say that practical educational supports for carers can impact on the quality of care of people with dementia and carer burden. While face-to-face interventions tend to yield the best results, telephone and web-based interventions can also provide cost-effective solutions to caregiver time constraints. Therefore, psycho-educational interventions which seek to reduce stress, depression and feelings of isolation among carers through the development of coping skills and resilience may be useful, as part of a comprehensive post-diagnostic support programme for people with dementia.

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There is increasing consensus that psychosocial interventions make an essential contribution to the support of people with dementia and their carers. However, the fact that the term ‘psycho-social intervention’ incorporates a range of different service models and elements such as social activity, emotional support, and psychological therapy, makes evaluation difficult. Moreover, the timing of diagnosis and subsequent care trajectory can determine the relevance and effectiveness of any potential psychosocial support. Reminiscence is very popular as a response to dementia, but the evidence with respect to its effectiveness is mixed. Studies in this area have mainly been small scale and confined to people with later-stage dementia, especially people living in nursing homes. A recent well-developed and well-designed trial casts doubt on the effectiveness of community-based joint reminiscence programmes for people with dementia and their carers. Similarly, the evidence on cost-effectiveness in this area is not supportive of reminiscence. This is not to undermine reminiscence as part of post-diagnostic support system, simply to acknowledge that the evidence is not strong in relation to impact and effectiveness. The same could be said about life story work for people with dementia.

Music therapy is another potentially valuable therapeutic approach and the most common form of arts therapy in post-diagnostic support for people with dementia. Like many psychosocial interventions, music therapy groups are a social activity, which promote interaction and communication between participants. This can potentially contribute to improving social skills among participants and help to reduce the risk of isolation. Music can also tap into personhood and an individual’s sense of self in relation to personal preferences. When asked about the value of music, people with dementia attest to its mental stimulating effects, emotional meaningful experience, its link to their personal identity and its ability to build and sustain relationships with others. Regardless of positive-leaning results from qualitative work, the results from a recent 2017 Cochrane Review on the effects of music-based therapeutic interventions are not encouraging. The authors found little or no effect on emotional well-being and quality of life, overall behaviour problems and cognition. There was moderate-quality evidence that music reduces depressive

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symptoms, but agitation or aggression was not reduced. The quality of the evidence on anxiety and social behaviour was very low, so effects were very uncertain. The evidence for any long-term outcomes was also of very low quality.

Exercise programmes for people with dementia can include a wide range of activities from simply walking across the room to more robust activities such as gardening and dancing. Research has consistently demonstrated that exercise has the potential to improve physical function for older people in all types of settings. Unfortunately, the overall evidence on the impact of exercise in dementia is not compelling. The most recent Cochrane Review found some evidence that exercise programmes can improve the ability of people with dementia to perform activities of daily living. But the evidence of any benefit for people with dementia from exercise on cognition, psychological symptoms or depression is weak. The quality of the evidence behind most of the results on exercise and dementia is very low. In relation to economics, one well-presented study suggests that exercise intervention has the potential to be cost-effective when considering behavioural and psychological symptoms, but is not cost-effective in relation to quality-adjusted life year gains.

So what should post-diagnostic support for people with dementia look like in the future in Ireland? The trend towards earlier diagnosis should continue, even if the costs and benefits of this approach are still not fully settled. Information matters for people recently diagnosed with dementia, even if we are still unclear what aspects of information matter most. Having a dedicated person to link directly with people newly diagnosed with dementia is important for continuity and the development of personalised care within an integrated system of provision. People with dementia and their carer need someone to help them navigate their way through existing services and supports. Whether that person is a dementia specialist from a clinical or social background requires further consideration, but, whatever their origins, they must have the leadership, expert knowledge and credibility to influence decision-making. The navigator should be a single point of contact for people with dementia within a specific geographical area, providing specialised dementia advice,

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information and support, as well as leading on the promotion of a personalised approach to service delivery across primary care teams and within the community care system.

Maintaining independence for people newly diagnosed with dementia should be the goal of the post-diagnostic support system. Keeping people connected to family, friends and social networks within local communities is really important. For that reason, education and psychosocial interventions, including peer support programmes, must become part of the care landscape to help people cope with the disease and its current and future implications. Cognitive stimulation should be central to any new post-diagnostic support system. This is one area where the evidence is clear in regard to the potential benefits for people with dementia. Innovation in reminiscence, music therapy and exercise should be supported and evaluated as part of a wider strategy of developing the bio-psychosocial model of care in Ireland.

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# 1. Introduction

Dementia is the general term for a decline in mental ability severe enough to interfere with daily life. Memory loss, although sometime seen as a natural part of aging, may also be an early sign of dementia, particularly if followed by a decline in other cognitive skills such as learning, thinking, reasoning, perception and problem solving. Behavioural symptoms, such as aggression and wandering, and psychological symptoms, such as agitation and delusions, are also frequently seen in dementia (Okahara et al, 2010). Dementia can take a number of different forms: Alzheimer's disease, vascular dementia, dementia with lewy bodies or mixed dementia, as well as other less common types such as Huntington's Disease, Parkinson's Disease and Creutzfeldt-Jakob Disease.

In Ireland, currently, there are just over 55,000 people living with dementia. The majority of these people do not have a diagnosis of dementia. As the country continues to age, the numbers of people with dementia is estimated to more than double over the next 20 years and triple over the next 35 years. While there is convincing evidence of the benefits of a timely diagnosis, (Woods et al, 2003; Knapp et al, 2007; Iliffe et al 2009; Banerjee and Wittenberg, 2009) the disease remains hugely undetected and under-diagnosed domestically and internationally (Cahill et al, 2012; Prince et al, 2011; Brooker et al, 2013;). Fewer than half of people with dementia in the UK ever receive a formal diagnosis (Banerjee and Chan, 2008; Milne 2010). Moreover, even when diagnosis occurs, there are often significant delays from symptom onset to that diagnosis, for example up to three years in Australia (Phillips et al., 2011). Longitudinal follow-up studies of population-based community-dwelling individuals have shown that cognitive impairment can be detected well before the onset of dementia symptoms (Saxton et al, 2004). Diagnosis, therefore, often occurs quite late, often after the illness has taken its toll on family life, and after it has caused huge distress to the individual and all those around him/her (Cahill and Pierce, 2013).

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A diagnosis does not just affect the person with dementia, but impacts on the lives of family and friends closest to them.

Dementia is a condition that largely affects older individuals over the age of 65, although people under the age of 65 can also be diagnosed with young-onset dementia. This type of dementia can occur when the person is as young as in their mid-thirties and makes them particularly vulnerable. The most recent estimates suggests that there are 4,311 people in Ireland with dementia who are under the age of 65 years (Pierce and Pierse, forthcoming 2017). People with early onset dementia can face additional complications. The financial implications of getting an early diagnosis of dementia can be severe; those in middle age will frequently be in paid employment (Harris & Keady, 2004; van Vliet et al, 2010), have different types of medium-to-long-term financial obligations (Flynn & Mulcahy, 2013; Harris & Keady, 2004), and be involved in parenting- children (Harris & Keady, 2004). Dementia can also affect people with intellectual disabilities including Down syndrome. People with Down syndrome are at an increased risk of developing dementia and experience it at a younger age. (Livingston et al, 2015). The National Institute on Aging in the US estimates that 50% or more of people with Down syndrome will develop dementia due to Alzheimer's disease as they age.

Research on the experience of receiving and living with a diagnosis is sparse. Despite its potential benefits, few published studies have explored the advantages or risks of a timely diagnosis of dementia (Dubois et al, 2016). It is clear, however, that people newly diagnosed with dementia need support to deal with the uncertainty and loss to identity and selfhood and to make positive adjustments to their lives through adopting specific coping mechanisms (Lee et al, 2014). Early intervention has the potential to improve the quality of life of patients and their informal family caregivers, both of whom are often relieved once a diagnosis is available (Boise et al, 1999; De Vugt and Verhey, 2013). Reduced uncertainty and the opportunity to come to terms with the diagnosis, seek support, and avoid crises were the most relevant

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advantages identified (Iliffe et al, 2003). The benefits for families included awareness of prognosis and disease course as well as the need to organize support, plan for the future, make appropriate legal arrangements, and optimize quality of life (Iliffe et al, 2003). A timely diagnosis at the prodromal stage may also improve patient access to support services or pathways of care and enable planning for the future (Dubois et al, 2016).

People with a diagnosis are, of course, only a small subset of those who are likely to have the disease. Some people may live with the symptoms of dementia for months or years before a diagnosis is confirmed (Mountain and Craig, 2012). The stigma attached to the disease means people may hold off visiting their GP even when symptoms arise; sometimes people with the disease never seek confirmation through diagnosis. GPs themselves face difficulties in making a diagnosis due to concerns about the negative impact a diagnosis may have on the person and their family. They may also be aware of significant care gaps for people diagnosed with dementia. Many people are left to cope on their own without support or information following a diagnosis. People who are faced with a life changing chronic illness, along with family members who are likely to become primary carers for the person with dementia, do not always receive the care and support needed in order to help them adjust to life with dementia. Diagnosis without adequate support may not, therefore always be beneficial and may, in fact, be detrimental to people with dementia and their families (Iliffe and Manthorpe, 2004; Manthorpe et al, 2013).

This current report is linked to the National Dementia Strategy's priority action area 'Timely Diagnosis and Intervention'. It was commissioned by the National Dementia Office as part of the post-diagnostic support pathway project. During the Consultation process for that National Dementia Strategy, there was general consensus that timely diagnosis is essential for ensuring early and effective interventions for people with dementia. There is growing evidence about the value of early intervention for the well-being of people with dementia and their relatives

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(Jones et al, 2002; Moretti et al, 2002; Moniz-Cook and Manthorpe, 2009). Early intervention can help improve patient self-efficacy, as well as enhancing dementia symptom management and behavioural change (Denning and Thomas, 2013). There is also evidence that early intervention can reduce the risk of subsequent institutionalisation for people with dementia (Gaugler et al, 2005; Banerjee et al, 2007).

Equally important in the lead-up to the National Dementia Strategy was the view that people with dementia need considerable emotional and practical support following a diagnosis (Cahill et al, 2012). The psychosocial potential of people in the early stages of dementia is likely to be considerable (Elvish et al, 2012), and they are capable of considerable insight in to the disease (Trigg et al, 2007), but they still need practical support mechanisms to allow them to adjust to a diagnosis. Post diagnostic support enables people with dementia to live better with disease, allowing people to come to terms with the diagnosis and a care plan to be put into effect, thereby contributing to a better quality of life for the person with the disease (Moniz-Cook et al, 2008). Post-diagnostic support can also lead to enhanced social contact thereby helping to reduce isolation (Clare, 2002). Keady et al., (2007) talk about the importance of post-diagnostic counselling to enable people to *'take on their diagnosis'* and *'work it through'*.

Post-diagnostic support can be the first step in the development of an individualised response to dementia. Post-diagnostic support can help alleviate the feeling of hopelessness that is often attached to a diagnosis, not only for people with dementia but also for their family carers. Receiving a formal diagnosis has the potential to allow the person to move forward and begin to put a care plan into action. However, without immediate support in the form of information, sign-posting or formal interventions for people with dementia at this critical juncture, the person with dementia can feel even more helpless with no one to turn to help them deal with the diagnosis and its aftermath. One of the most consistently referenced issues by people

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with dementia and their carers is the availability and appropriateness of support offered following confirmation of diagnosis (Mountain and Craig, 2012). The aim of this literature-based study is to explore the international evidence with respect to post-diagnostic support in order to provide guidance to the National Dementia Office as they seek to develop policy and priorities in this area in Ireland.

According to Clare (2002) post-diagnostic support should include activities that enhance or provide social contact and peer support to reduce isolation, provide information and opportunities to overcome limitations on them by the condition and preserve or bolster self-worth by finding ways for them to make a contribution and to feel useful. The Social Care Institute for Excellence (2014) have provided a more formal definition of post-diagnostic support for people with dementia as follows: *the main aim of post-diagnostic support services for dementia is: to help people to continue living well in the community; provide information and support; help people to manage issues as a result of getting a diagnosis; and delay admission to long-term residential care.* It is very important that post-diagnostic support is provided directly to people with dementia. When people with dementia feel that support is aimed at family members rather than at them, the result is often increased feelings of powerlessness and helplessness (Mountain and Craig, 2012). Post-diagnostic support should, therefore, be eclectic in its origins and ambitions, focusing on the disease, the people that have it and the people who care; that means a focus on care relationships, social connectivity and the care pathway. There is myriad of potential supports, ranging from information and advice, to psycho-educational supports, peer support activities like dementia cafes, cognitive rehabilitation and stimulation and a raft of potential psychosocial interventions depending on the stage of the disease, which includes reminiscence, music and exercise. Choosing the most appropriate supports depends on the timing of the diagnosis and the stage of the disease when it occurs.

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Diagnosis does not occur at a set time for people with dementia; for some, diagnosis may not come at all, for early onset dementia, diagnosis can come very early in life, for the majority of people it comes later in life. People of different ages, at different stages of the disease will have different needs, some of them more immediate than others. Therefore, what might constitute as a post-diagnostic support for one person may not suit the needs of another. Providing information and advice is often thought of as the first step following a diagnosis – a basic component of post-diagnostic support. However, for someone far along in the disease, this may not be the case. Instead, accessing residential care or behavioural medication may be the immediate priority for someone who has had dementia for a long time, but remained undiagnosed until very late in the disease. Post-diagnostic support works best, therefore, when it is personalised and responds to the expressed needs of the person diagnosed, depending on where the person is on the continuum of need. But that sometimes makes it very difficult to define post diagnostic support, or to differentiate it from usual care or standard psychosocial interventions for people with dementia at any point on the dementia care pathway.

Policy-makers across the world have become very interested in post-diagnostic supports for people with dementia The World Alzheimer Report (2009) and the WHO (2012) report *Dementia: A Public Health Priority* directly reference post-diagnostic support in their seven-stage model for planning dementia services. Both WHO and Alzheimer Disease International outline the importance of post-diagnostic support in enabling people with dementia and their caregivers to come to terms with the disease, plan for the future and make the best use of their current circumstances. The focus is on the strengths of the person with dementia, on allowing people to continue to do what they can still do rather than concentrate on declining abilities. That viewpoint is explicitly referenced in the national dementia strategies of many different countries, for example Scotland, where there is explicit reference to improving post-diagnostic information and support. The Irish National Dementia Strategy incorporates post diagnostic supports in its priority actions, through its

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support for information and training, as well as named key workers within primary care services to co-ordinate care and continuity, thereby ensuring easy access to appropriate information and advice.

There is universal agreement that post-diagnostic support for people with dementia and their carers is an important part of the care infrastructure for dementia. The early identification and intervention in dementia has been shown to improve quality of life, and delay the need for institutionalisation (Department of Health, 2008). According to Gaugler et al, (2005), the early provision of support at home can decrease institutionalisation by 22%. *Similarly*, carer support and counselling after diagnosis can reduce care home placement by 28% (Mittleman, 2007). It is understandable, therefore, that the concept is enshrined, either directly or indirectly, in government thinking and policy narratives about appropriate responses to dementia. The difficulty is, however, that there is little evidence to draw clear conclusions from in regard to the usefulness of many of post-diagnostic supports that are currently available to people with dementia and their families (Kelly and Innes, 2016). We are often left to rely on the views of service providers and expert opinion on the merits of diagnostic supports rather than carefully designed research studies focused on the costs and benefits of various interventions. While these views and opinions are valuable, they are not the same as rigorous evaluation and there is always some reluctance, therefore, to use them as conclusive evidence that something works, or that one kind of approach is better than another. The difficulty, however, is the quality of the scientific evidence on non-pharmacological approaches to dementia is equally problematic and very often falls into the '*might work*' category (Hulme et al, 2009), making it difficult for policy-makers to make informed decisions (Moniz-Cooke and Manthorpe, 2009). In the chapters that follow, we bring together the international evidence in relation to post diagnostic support, in an effort to establish some guidelines for policy-makers in Ireland for future investment in this area in Ireland.

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## 2. Methodology Issues

There is an absence of methodological work on post-diagnostic support for people with dementia. This is due to uncertainty and variability with respect to the timing of diagnosis for people with dementia. Needs are likely to be very different for people at the early stages of the disease compared to those in the later stages. Consequently, there is no certainty in relation to optimal bundles of post-diagnostic support for people with dementia. It depends on where people are along the continuum of the disease. However, the NICE-SCIE Clinical Guidelines 42 (2006) does provide some general guidance on people's right to be fully informed about care following diagnosis and to make decisions in partnership with the care team. The Guidelines state clearly that unless otherwise decided by the person with dementia, the care team should explain:

- the type of dementia that the person has
- details about symptoms and how the illness might develop
- treatments
- care and support services in the area
- support groups and voluntary organisations for people with dementia and their families and carers
- advocacy services
- where to find financial and legal advice.

The Guideline also says that the person with dementia should be given written information about dementia. The Guideline is useful in establishing a baseline for intervention following a diagnosis of dementia and is used to inform the literature search and subsequent analysis in this report.

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Mountain and Craig (2012) developed a draft self-management programme for people with early stage dementia covering a lot of the key issues in this area. They used participative research methods to obtain views from people with dementia and carers about their experiences and the interventions that might assist in facilitating independence and quality of life post-diagnosis. Twelve topics were identified as being important for self-management, most of them capable of being influenced by post diagnostic support programmes (Table 2.1). This blueprint, although embryonic and not fully developed, as well as being more focused on self-management, also influenced the literature search in relation to post-diagnostic support and the subsequent analysis of that literature.

**Table 2.1: Topics for Dementia Self-Management (Mountain and Craig, 2012)**

<b>Topic</b>	<b>Dimensions</b>
Understanding dementia	Full and timely information about the condition and what to expect
Rethinking dementia	Dementia as part of a process for change, health well-being and activity, enabling environments
Living with dementia	Making the most of routines, memory maintenance, strategies to manage memory loss
Relationships	Building and maintaining friendships, rediscovering relationships
Keeping mentally well	Recognising and overcoming depression, managing anger, managing anxiety
Experiencing well-being	Volunteering, hobbies, leisure
Dementia and daily living	Using everyday technology, managing finances, home and community safety
Keeping physically well	Eating and nutrition, sensory impairment, developing healthy bladder and bowel habits, managing medication, sleep, managing fatigue, managing other physical conditions
Building and developing skills	Grading activity, problem solving strategies, learning new skills
Keeping connected	Maintaining community connectedness, accessing outside opportunities, transport and driving
Maintaining a sense of self	Dressing and identity, self-esteem, spirituality, keeping faith
Planning for the future	

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A more explicit framework for thinking about post-diagnostic support is Gilmour's (2011) 5-pillars model developed for Alzheimer Scotland. The 5-Pillars model provides a framework for people with dementia, their families and carers to allow them to live as well as possible and prepare for the future. The five pillars are: supporting community connections; peer support; planning for future care; understanding the illness and managing symptoms; planning for future decision-making. The model was adopted by the Scottish authorities as part of their dementia strategy whereby every person with a diagnosis of dementia in that country is entitled to one year of post diagnostic support. It provides a useful cross-reference in this study when exploring the international literature for potential interventions that impact any or all of these five pillars.

A comprehensive literature examination of the best available evidence and most effective post-diagnostic supports for people with dementia was conducted for the purpose of this report over a period of ten weeks. Searches of online databases: Cochrane, Scopus, PubMed, NCBI, ALOIS and the NUIG library websites were carried out to find papers which provided information on post-diagnostic support in dementia care. A search including the words post-diagnostic support, post-diagnostic, supports, dementia, diagnosis, carers, caregivers, intervention, rehabilitation, cognition, Alzheimer's disease, or various combinations of those words. The original search terms were then used in combination with terms appropriate for each type of potential intervention, such as: *information, counselling, cognition, or psycho-educational interventions for carers*. A search for cost-effectiveness studies for each potential intervention was also conducted. A separate search was conducted on post-diagnostic support for people with Down syndrome and dementia. Only papers with the strongest evidence on each of the potential post-diagnostic supports are reported in this review. Greater weight in the reporting is placed on trials, systematic reviews and meta-analyses.

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National dementia strategies were examined for 33 countries to explore the use and role of post-diagnostic supports in domestic policy narratives in the past decade. Online resources such as Alzheimer Europe and recent comparative literature were used to gather information on the dementia strategies of the various countries. Only countries with published dementia strategies or plans were included in the initial screening. The search was focused initially on strategies that referred directly to post-diagnostic support, or made reference to the support and care of people recently diagnosed with dementia. Only a very small number of countries made direct reference to post-diagnostic support, so the search was extended to include countries that incorporated both direct and indirect reference to post-diagnostic support.

The purpose of this report is to provide guidance to the National Dementia Office in regard to the evidence in relation to post-diagnostic supports in dementia. It should be acknowledged, however, that the diversity of care provision following diagnosis makes it impossible to compartmentalise interventions into neat and distinct categories. There is no clear agreement on the constituent elements of post-diagnostic support within the broad definitions that exist, nor on who should be the primary beneficiaries of those supports. For the purposes of this report, we have loosely divided post-diagnostic support into four categories as follows:

- information, advice and peer support
- cognitive therapies
- psycho-educational supports
- psychosocial supports

There will be considerable overlap across these categories. While some research projects cover only one aspect of post-diagnostic support, there are many examples of multi-component studies covering a range of services. Before discussing each category separately, the next chapter looks at how post-diagnostic support is

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expressed within the dementia strategies of other countries and whether Ireland can learn anything from its positioning within national and international policy frameworks for dementia.

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### 3. Post-Diagnostic Support in Other Countries

Ireland can learn from the approach taken to post-diagnostic support in other countries. An in-depth look into the dementia strategies of various countries allows a comparison to be made between policy in Ireland and the rest of the world. It also provides an opportunity to learn from other countries and help to identify the services and interventions that best support an individual in the period following diagnosis. A very small number of countries actually use the term ‘post-diagnostic support’, but nearly all countries are conscious of the need for appropriate interventions post-diagnosis. All countries place a value on supporting the person with dementia following a diagnosis and many share similar objectives in relation to post-diagnostic support, even if that term is not explicitly used.

Dementia is a progressive disease with no cure. A timely diagnosis can facilitate a better understanding of the disease, symptoms can be managed, including progression to some degree. However, the majority of the estimated 35,000 people living at home with dementia in Ireland do not have a formal diagnosis (Cahill et al, 2012). Diagnosis issues are, however, not unique to Ireland. Target 4 in the WHO Global Action Plan on the Public Health Response to Dementia (2016) shows how much more remains to be done in relation to diagnosis across the world. By 2015, the WHO have set a target that *‘in at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed’*. Even if that target is met, the majority of people with dementia will still be undiagnosed in 2025. Even when diagnosis does occur, it is often given too late on in the disease when basic post-diagnostic support, in the form of information and advice, is no longer enough to support the person with dementia to live well in the community.

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Ireland launched its own National Dementia Strategy in December 2014 (Department of Health). Section 5 of the Strategy deals with timely diagnosis and intervention. A key objective of the Strategy is that *'following a diagnosis, people with dementia and their carers know where to seek help or support, who to talk to about accessing services or entitlements and where to go for information'*. It was acknowledged in the Strategy that the availability of relevant information and guidance can greatly assist those who have dementia and those who care for them. There is a lot of uncertainty following a diagnosis and very often people do not know who to contact to find out more about the disease, or where to access appropriate services or statutory entitlements. The information needs of people with dementia and their carers were set out in the Irish National Dementia Strategy as follows:

- Signs and symptoms of dementia
- Its course and prognosis
- Medications
- Local care and support services
- Support groups
- Source of financial and legal advice and advocacy
- The income supports available for those with an illness/disability and for those with care responsibilities
- Medico-legal issues, including driving
- Local information sources, including libraries and voluntary organisations

The Strategy included priority actions in the following themed areas: better awareness and understanding; timely diagnosis and intervention; integrated services, supports and care for people with dementia and their carers; training and education; and leadership. While post-diagnostic support is not explicitly referenced within or across these themes, it is possible to identify priority actions that reflect a concern and support for various interventions immediately following diagnosis. The relevant priority actions referenced in the Strategy can be summarised as follows:

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- national and local dementia care pathways
  - GP training and information
  - training and education to other relevant occupational and professional groups
  - information routinely given to people with dementia and their families on how to access advocacy services, voluntary organisations and other support services
  - named key worker within primary care services to co-ordinate care and continuity, as well as ensuring easy access to appropriate information and advice.

An additional relevant action in the Strategy is the commitment that the HSE will consider the provision of Dementia Advisors on the basis of the experience of their usefulness in demonstrator sites established by the Alzheimer Society of Ireland, with an appropriate number of such Advisors to be dedicated to the needs of those with early onset dementia. Since the publication of the Strategy, progress has been made in developing appropriate responses to a diagnosis of dementia. Training and education programmes have been developed, peer support programmes, such as dementia cafes, are now more evident and information networks have been enhanced. The Dementia Advisor service is also currently being evaluated with a view to acting on the lessons that emerge for the expansion of the service beyond the current limited number of sites. However, it is also true that post-diagnostic support services remain fragmented, under-resourced and confined to urban areas of the country.

Dementia has become an increasingly important policy issue worldwide, mainly due to prevalence issues and the cost of care. Policy makers in many countries have developed a National Dementia Strategy or Dementia Plan in response to the issue. Some countries are in the process of creating a second, or even third, updated

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Strategy. The various strategies and plans that are now in place are relatively consistent regarding what needs to be done. There is an emerging common language in regard to post diagnostic support across the various countries, expressed in a variety of forms for a variety of circumstances. Multiple countries have placed an emphasis on: helping to keep an individual as independent as possible; helping to manage symptoms; support for family and carers; making information and advice available; making services available; supporting community connections and making new ones; helping in planning for future needs while including all those affected in the decision making process; and offering seamless care through the integration of health and social care professionals, creating a multi-sectorial delivery of support. Other features frequently mentioned are medication management and palliative care, both of which depend heavily on the timing of the diagnosis. Countries have recognized that without a plan to address dementia, individuals will not have access to the specialist services and supports they require.

Most country plans do not reference post-diagnostic supports directly. Only two countries, Scotland (Scottish Government, 2013) and Gibraltar (Government of Gibraltar, 2015), have integrated the term into their strategies, while Norway (Norwegian Ministry of Health and Care Services, 2015) refers to post-diagnostic follow up. However, information provision is central to most countries response to dementia. National strategies have supported the broad concept of information provision under a variety of objectives or priority actions such as: *'ensure a good quality of life for people with dementia and carers'* (Finland, Ministry of Social Affairs and Health, 2013); *'support and information for individuals with dementia'* (Australia, Australia Dementia Working Group, 2015); *'advance directives on care choices'* (Canada, Standing Senate Committee on Social Affairs, Science and Technology, 2016); *'early diagnosis and support'* (England, Department of Health, 2009); to name just a few. A common theme across these countries is the emphasis on the importance of information and advice for people with dementia and their carers to enable them to live well with the disease and make better decisions. The stakeholder

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consultation for the English Strategy (Alzheimer's Society, 2009) identified a lack of coordinated information services for people with dementia and their carers, which led to the development of nationwide Dementia Advisor service in that country to provide information, advice and signposting.

The emergence of a common language in support of diagnostic care is evident in the work of Fortinsky and Downs (2014) in their examination of transitions in the dementia journey across seven countries: Australia, England, France, Netherlands, Norway, Scotland and the USA. For example, In Australia's national dementia strategy (Australia Dementia Working Group, 2015) support after diagnosis is mentioned as important to engage people affected by dementia in making informed decisions about their future care. That engagement should be person centred and individually tailored to meet changing needs, while supporting family caregivers via training, counselling, and access to support groups. Objective 4 of England's national dementia strategy (Department of Health England, 2009) focused on making it easier for people to access care, support, and advice following a diagnosis of dementia. The Strategy helped establish forty demonstration sites where people with dementia and their caregivers could access support from dementia advisers and peers.

The emphasis in France has been to strengthen the coordination between all stakeholders following diagnosis. This objective explicitly states that support after diagnosis must be *'seen from the viewpoint of the patient and his or her family in order to organise the system around their needs'* (Republic of France, 2008). The importance of a single point of contact to access treatment and services as soon as the diagnosis is made was emphasised. The Netherlands also sought to create a coordinated range of person-centred options that meet patients' needs and wishes following diagnosis of dementia (Ministry of Health, Welfare and Sport, 2009). Timely information and case management were considered essential for the delivery of guidance and support for people with dementia and their families. Education and supporting individuals and families after diagnosis was also considered important in

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the USA strategy as a way of managing various transitions across the care continuum (US Government, 2012). Scotland's national dementia strategy specifically identifies post-diagnostic information and support as a key service delivery area. The self-management of dementia and its symptoms is explicitly included among the objectives of an improved infrastructure for information and support after diagnosis (Scottish Government, 2013).

Other countries have devised a number of actions which fall broadly into post diagnostic support for people with dementia and their families. Finland places an emphasis on rehabilitation services in order for people with dementia to be able to continue living in their own homes. In Israel, health services are seen as a major element in the treatment and support of people with dementia. Recommendations include informing family on the progress of the disease and the types of treatment and supports available in the health system. Increasing referrals to non-medical treatment such as psychosocial interventions is also referenced as an objective in Israel's National Dementia Strategy (State of Israel, Ministry of Health, 2013). Switzerland has established individualised information and social counselling services for affected individuals, integrated into existing services such as Alzheimer's Association (Swiss Federal Office of Public Health, 2014). The Maltese government also work with local non-government organisations in order to provide community and peer support to individuals with dementia, caregivers and families (Parliamentary Secretariat for rights of persons with disability and aging, 2015). In Belgium, psycho-education, tailored to informal caregivers, has been developed and enhanced with the aim of increasing the capacity and quality of life of both parties in the care relationship (Ministry For Welfare, Public Health and Family, 2016) A dedicated dementia helpline has been developed in Wales to support the psychological and emotional needs of callers, including people recently diagnosed with dementia and caregivers (Welsh Assembly Government, 2011).

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One of the strongest features of national dementia strategies is support for Dementia Advisors. The latter can play a vital role in the initial stages after a diagnosis is made, evidence of which can be seen across a number of countries. A Dementia Advisor can help and advise the person with dementia and their family in putting together an integrated personalised care plan. Dementia Advisors are, for example, central to the English dementia strategy. Scotland, has introduced the concept of a dementia link worker. Similar to dementia advisors, they are specifically trained in post-diagnostic support, working alongside the family and linking directly to the health and social care structures. The Scottish approach guarantees up to 1 years' continuous care, in which time a personalised care plan is created (Scottish Government, 2013). This gives people the time and space to access high quality supports and adjust to the illness. Link workers are also mentioned in the National Strategy of Gibraltar, as a means of providing a post-diagnostic support package for one year after diagnosis (Government of Gibraltar, 2015). Comparable to this is the *first link program* implemented recently in Canada. The first link is a referral program designed to help newly diagnosed people with dementia get the help they need as soon as possible (Alzheimer Society Canada, 2016). France has also established the concept of dementia coordinators, who work through a case management approach, to link up services for people with dementia and their families.

Although post-diagnostic support is sometimes time limited to within a year of diagnosis, as in Scotland and Gibraltar, the vast majority of countries do not specify a time limit for various interventions. Instead, there is an emphasis on continual customised care that is tapered, adapted or enhanced as appropriate. Multiple supports are mentioned as beneficial throughout the course of the disease, from when the person first receives a diagnosis up until end-of-life care in some countries. That makes it very difficult to determine when post diagnostic support begins and ends in various countries, or whether support along the continuum of care is as seamless as predicted in published dementia plans. Indeed Scotland, the country most associated with post-diagnostic support, is now committed to improving the

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various transitions that occur across the care continuum. Post-diagnostic support is influenced by the timing of diagnosis; supports that work in the early stages of the disease may not be appropriate in the later stages of the disease.

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## 4. Information, Advice and Peer Support

Upon receiving a diagnosis of dementia, many people are left feeling lost, confused and in need of assistance. The person with dementia as well as family members may be unaware of what dementia entails, its progression or what services and treatments are available. People with dementia come into contact with a range of health and social care services. Knowing where and how to access particular information or a certain service can be confusing for people with dementia and carers'. Therefore, timely advice on how to proceed is crucial once a diagnosis has been made to help the person adjust to their condition. Information on the disease itself is not the only aspect that must be dealt with. As people come to terms with their diagnosis, future arrangements may also need to be made in a variety of areas, including care supports, care relationships, financial issues, benefits, work and leisure. Once the disease progresses, communication and independent thinking are reduced, making decision-making more difficult.

Dementia also impacts the lives of those closest to the person such as family members, family carers and friends. They often have just as many questions as the person with dementia. It is important, therefore, that those dealing with the person on a daily basis are well informed about the condition and its progression. A clear understanding of the disease helps give the carer an insight into the attitude and behaviour of the person with dementia. Knowing that services and supports exist may also allow the carer to cope better; they have the confidence and security that they are not expected to bear the caring burden on their own.

Consultations with people with dementia and carers have highlighted that timely, well-targeted information services are a key priority for enabling them to 'live well with dementia' (Corbett et al, 2012). Nearly half the respondents of a questionnaire on information needs in Ireland reported '*not knowing where to go to get the*

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*information you need'* as a constraint to good quality care. A number of different aspects of information provision have been identified in the literature including: support at the time of diagnosis; general information about dementia that is appropriate to the stage of the condition; information regarding access to locally available services and advice; and support provided by a single named contact. Empirical research in North America also supports the potential value of information services (Teri et al, 2005). But the research also indicates that people living with dementia currently find it difficult to get information, advice and support about their diagnosis, and access to appropriate services throughout their life with dementia (La Fontaine et al, 2011). Moreover, when research has been done, it has focused more on the impact of information and related peer support activities on caregivers rather than on people with dementia (Corbett et al, 2012). The research has also lacked specificity, making it difficult, for example, to determine what particular aspect of information and advice provides the most benefit for people with dementia and caregivers.

The lack of support offered by GPs and specialists force many people with dementia to seek out information and advice themselves, online or through voluntary organisations. Numerous services have been set up to provide helpful resources for information, education and support. In the UK, support provided by charitable/voluntary services were deemed satisfactory or better than support from GPs (National Audit Office, 2007). In Ireland, organisations such as The Alzheimer Society of Ireland and the HSE, through the *Understand Together* website, offer information on services and support which may be useful to anyone seeking advice on the disease (Health Service Executive, 2017). The Alzheimer Society of Ireland provide a range of specialist information services throughout Ireland, including: national hotline; dementia advisor service; social clubs; and Alzheimer's café. Supports for family members and carers are also provided in the form of family education programmes, family support groups and respite care. They also provide practical tips for living well with dementia (The Alzheimer Society of Ireland, 2017).

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A systematic review by Lauriks et al (2007) gathered data relating to the effects of information and communications technology on the unmet needs of people with dementia. As part of the review they examined 18 relevant websites that provided general and personalised information for people and their carers' on dementia, services and supports, financial and legal advice and care planning for dementia. They found that digital information is extensively provided, but with varying quality. Many of the websites examined included information and tips and support for carers' but less information was available for the person with dementia. The authors concluded that the digital information presented is often too generic in nature; not surprisingly, personalised information is still difficult to obtain online (Lauriks et al, 2007). Web design was also less attuned to the needs of the person with dementia.

Evidence on how information services, irrespective of who provides them, affect a persons' quality of life, their neuropsychiatric symptoms and the carers' level of burden is critical to determine whether such services are of benefit and if they are cost-effective. That evidence is currently weak, with very few studies focused solely on the effects of information provision alone. The majority of published studies have incorporated elements of other services in addition to information provision. Corbett et al (2012) conducted a systematic review of information and/or advice to people with dementia and/or their carers'. They gathered data on 13 RCTs which focused predominantly on the provision of information. Their analysis illustrates how information services provide modest benefits for people with dementia in relation to quality of life and the prevention of neuropsychiatric symptoms. Surprisingly, there was no overall benefit in relation to caregiver burden. The study does provide support for the usefulness of information and advice services as part of a complex, multi-component intervention for tackling dementia. The overall conclusion from the systematic review is that while there is certainly support for the value of information services in the literature, more studies are needed to determine the specific elements that are effective within such programmes. (Corbett, 2012).

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A key aspect in information and advice provision and signposting is the role of Dementia Advisors. No single health or social care professional has the capacity or knowledge to provide all the information needed for people with dementia, resulting in a specific role/title of Dementia Advisors being introduced in some countries. Dementia Advisors can help to reduce the risk of gaps in information by creating knowledge platforms for dementia, collaborating with health and social care services, keeping health records up to date and passing on accurate and timely information to people with the disease and their family carers. A named dedicated contact is often more practical than a team of different health care professionals, which can create confusion and inconsistency in relation to information provision. In brief, the role of a Dementia Advisor is to work with individuals and their families, giving information and advice in a timely manner, directing people to appropriate agencies and supporting them throughout their journey (De Siún, 2013).

Dementia Advisors have been included in the National Dementia Strategies of a number of countries, although their title and role tends to vary from country to country. Dementia Advisors in England act as a central point of contact for people with dementia, identify problems and provide signposting to services and supports. France established Dementia Co-ordinators who have a broader range of roles than simply the provision of information and advice. Link Workers were introduced in Scotland to provide a minimum of one years' person-centred support to people with dementia in line with 5 pillars model of post-diagnostic support designed by Alzheimer Scotland. Ireland now has a small number of Advisors providing individualised information and signposting service and supports for people with dementia and their carers (The Alzheimer Society of Ireland, 2017). Based on the experience of their demonstration sites, Genio (2016) have suggested a dementia specialist from a clinical background for this role in Ireland, to provide expert knowledge and coordination of services. The resource should be a single point of contact for a designated area providing specialised dementia advice, information and

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support; raising community awareness and understanding; and most importantly leading on promoting and embedding a personalised approach to service delivery across primary care teams and associated services.

In 2013, the Department of Health in England reported its results of an evaluation of peer support networks and dementia advisers through the Healthbridge project (Clarke et al, 2013). In recognition of the range of roles played by dementia advisers, 40 demonstration sites were used to assess the effectiveness of dementia adviser services, their contribution to achieving UK National Dementia Strategy objectives and their influence on the well-being of people with dementia and their carers'. The evaluation included activity and outcome monitoring, organisational surveys and in-depth case studies. Key findings included: the importance of timing and flexibility for individualised support; enabling people with dementia and carers to find meaning and value in their new life; signposting to appropriate services; and raising community awareness and understanding of dementia. In terms of design and development, the evaluation noted that Dementia Advisors filled the gap in information by working with pre-existing services and supports, resulting in resource saving for health and social care (Clarke et al, 2013). The report concluded that Dementia Advisor services and associated peer support networks combined successfully to meet the information needs of people with dementia and carers' in England. They had a significant role in enabling people with dementia and carers to re-narrate their lives, finding a new life which, though different from life prior to dementia, had meaning, value and purpose and in signposting people with dementia and carers to appropriate other services and support.

The ongoing Actifcare project acknowledged the use of information and care co-ordination in helping people with dementia and their carers' access services in a timely and appropriate manner (Broda et al, 2017). Actifcare is a European study aiming at best practice development in finding timely access to formal care for community-dwelling people with dementia and their carers (Kerpershoek et al,

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2016). The Actifcare study, through literature reviews, focus-groups, expert interviews and a cohort study found that barriers regarding access to care services were due to a lack of services and supports in general and a lack of knowledge among people with dementia, carers and health care professionals. The role and importance of Dementia Advisors was highlighted, especially by UK experts, as a means of providing relevant and useful information. Experts in other countries highlighted the need for some form of co-ordination role, through key workers, link workers or case management. Whatever the process, timely contact is important following diagnosis, followed by individualised information and continuous support and advice (Broda et al, 2017).

Scotland's Health Improvement, Efficiency, Access and Treatment (HEAT) Standard from April 2013 is that everyone newly diagnosed with dementia is entitled to be offered, at minimum, a year's worth of post-diagnostic support, coordinated by an appropriately trained Link Worker (Scottish Government, 2013). Alzheimer Scotland's 5 Pillars Model of Post Diagnostic Support, referred to earlier in this report, offers strategies, connections and resources on how to plan living as well as possible with dementia and to prepare for the future. All people with a diagnosis of dementia are guaranteed a minimum of one year of appropriate post-diagnostic support. The development of the 5-Pillar Model and the post-diagnostic service offer was originally framed with a focus on people receiving an early diagnosis and living at home or in the community, with little formal health or care service support required in the initial period.

Feedback from people receiving this post-diagnostic service in Scotland is that it works well. An evaluation by Kelly and Innes (2016) identified the potential of post diagnostic support to increase independence, self-motivation and confidence, through the provision of one-to-one individualised support, socialisation with peers and wider society and accurate, timely information in a format and pace that suits people with dementia and caregivers. However, recent research on dementia incidence in Scotland (Scottish Government, 2016) has shown that increasing

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numbers of people are being diagnosed later in life and that many of these already have significant care needs. Such people are eligible for post-diagnostic support, but may already be receiving, or need, substantial support for other long-term or chronic conditions, or for palliative care; some may also be in residential care settings. This raises the question of the relevance of existing 5-pillar post-diagnostic supports for people diagnosed late in the disease.

For the next stage of the Scottish Dementia Strategy 2017-20, people newly diagnosed with dementia will receive appropriate support following diagnosis, with that support being either (a) the current 5-pillar model of post-diagnostic support, or (b) care coordination, based on an 8-Pillar Model of Integrated Community Support, incorporating a wider choice set of care and supports. The latter provides a useful platform for coordinated care to support people with dementia living at home during the moderate to severe stages of the illness. The approach centres around a Dementia Practice Coordinator who provides tailored post-diagnostic support, while at the same time increasing the level and focus of integrated care coordination (Scottish Government, 2017). The transition from post-diagnosis to integrated care, from link worker to dementia practice co-ordinator, is delicate and requires careful monitoring and co-ordination if it is to be successful. Having one named person throughout this pathway, rather than different support workers, is probably the ideal, but putting this into practice may not be easy. Flexibility is required to address the issue of timing in regard to diagnosis and the differences in care needs following that diagnosis. The Scottish government have promised to evaluate the various transitions and complexities involved in any new arrangement designed to address complications arising from the timing of diagnosis. This experience points the need to have a single comprehensive role with specialist skills covering the functions of link workers and practice coordinators, to avoid the need for the person with dementia to make several transitions and also to cut down on complex coordination. This comprehensive role is akin to the Dementia Coordinator role demonstrated in several sites in Ireland (Genio, 2016).

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Information networks have also been enhanced in recent years through peer support networks such as Alzheimer's cafés (Miesen and Jones, 2004). They were first developed about 20 years ago in the Netherlands. An Alzheimer's café is a regular (often monthly) post-diagnostic group intervention that provides education and information about dementia and various types of support in a relaxed social setting. People with dementia can visit a café and meet others in similar situations to themselves. By talking to people going through similar experiences, personal, relatable information and advice can be shared. Simply generating conversation about dementia can enhance the information set available to all people who attend the café. Experts in dementia care are often invited to attend the café, thereby stimulating additional conversation and broadening and deepening information on dementia for attendees. Dementia cafes have a strong intuitive appeal, but there is very little evaluation on their advantages and disadvantages for people with dementia and caregivers.

Dow et al (2011) evaluated three cafes in Australia using a mixed methods approach, including focus groups and surveys. The results indicated that the cafes helped to promote social inclusion and peer support, as well as improving the social and emotional well-being of attendees. Peer support was enhanced through social interaction, as people formed lasting friendships beyond the boundaries of the cafes. The cafes improved attendees understanding and knowledge of dementia and facilitated access to other services. The café experience also helped to prevent isolation for people with dementia and caregivers. However, cafes did not meet everyone's requirements, particularly in relation to cultural and linguistic needs. Moreover, it is impossible to read too much into the results given the small scale of the study and the site specific nature of the analysis.

Another qualitative study on carers' experience of dementia cafés highlighted significant benefits associated with the experience (Greenwood et al, 2017). Although the study was again very small, open to selection bias and confined to carers, who

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were recruited from five cafes in and around London, four main themes were identified: an opportunity for carers to enjoy themselves and switch off from being a carer; cafes as normalising living with dementia; peer support; developing social networks and reducing social isolation. Participants felt that the café offered stimulating activities for both the person living with dementia and their carers, peer support and an opportunity to socialise with others in a relaxed space. One very important finding was that cafés helped to normalise dementia through allowing people to be themselves without having to worry about what other people thought about them. The flexibility provided through the cafes was also highly valued by participants.

It is clear from the literature that people with dementia and their families still find it difficult to get information, advice and support about their diagnosis in a timely manner. When that information is provided it is often generic in nature and of variable quality. Moreover, the information is often geared to the needs of carers rather than to the needs of the person with dementia. Trials have not succeeded in identifying specificity in relation to the effectiveness of information provided. While there is evidence to support the provision of information, the breadth, depth and quality of existing studies is poor and further research is needed to understand which particular aspects of information are effective (Corbett et al, 2012). There is general cross-country agreement of the importance of a single point of contact for people with dementia, particularly in relation to information and signposting services. Different labels are used in different countries to describe that contact person, such as dementia advisor or dementia link worker – the common denominator being that the person works primarily with people with dementia and their caregivers. What the advisor or link worker does is to identify potential solutions to the problems of people with dementia and ensure that they get access to the services they need at the right time and in the right place. For all the stakeholder consensus on the importance of this role, there is limited research evidence on its overall effectiveness for people with dementia or their families. Similarly, although the literature on the role of

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dementia cafes as a peer support mechanism for people with dementia and caregivers is generally supportive, the number of studies is very small, making it difficult to make a convincing case for investment in cafes, in the absence of more complete information.

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## 5. Cognitive Therapies

Cognitive decline is often an early sign of dementia. A person with mild cognitive impairment (MCI) is at an increased risk of developing dementia. Cognitive deterioration leads to the decay of functional ability and contributes to health care expenditure ten times greater than for those without such deficits (Jutkowitz, 2017). It can cause a person to lose their independence as they become reliant on someone else to help with their thinking and decision making, contributing towards disease progression. Difficulties with memory or cognition can often interfere with a person's ability to recall names or events or carry out specific tasks or activities. In many cases, people may not have any specific area of concern but wish to address more general memory problems. Preserving cognitive and social functioning, through 'mental exercise' can help to counter or slow down the decline in memory (Salthouse, 2006).

Cognitive stimulation is one type of 'mental exercise' that may impact on dementia. Cognitive stimulation has been described as a cognitive-based non-pharmacological intervention that targets cognitive and social functioning (Clare et al, 2003). The intervention is usually undertaken in a group setting or with the family caregiver (e.g. Onder et al, 2005), and the activities included in the programme address general stimulation of cognitive abilities (Clare and Woods, 2004). Practically, cognitive stimulation involves a wide range of activities aimed at stimulating thinking and memory generally, including discussion of past and present events and topics of interest, word games, puzzles, music and practical activities such as baking or gardening. Typically, this is carried out by trained staff with a small group of four or five people with dementia for around 45 minutes, at least twice a week. Family caregivers can also be trained to provide cognitive stimulation to their relative on a one-to-one basis.

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The roots of cognitive stimulation can be traced back to reality orientation. The latter was initially developed and offered in the USA as a therapeutic process for older patients who were experiencing confusion and disorientation. It operates through the presentation of orientation information (for example, time, place and person-related) designed to provide the person with a greater understanding of their surroundings, thereby potentially enhancing sense of control and self-esteem. A Cochrane review by Spector et al (2000), based on six RCT's comprising 125 respondents, concluded that reality orientation led to improvements in cognition and behaviour for people with dementia. It was unclear, however, how far the benefits extended after the end of treatment.

Systematic reviews have found cognitive stimulation to be a psychosocial intervention for people with dementia which has robust evidence (Livingston et al, 2005; Olazaran et al, 2010; Woods et al, 2012). The ever-growing body of evidence has consistently shown the benefits of using it to improve cognitive functioning and quality of life for people with dementia. A Cochrane systematic review conducted by Woods et al (2012) combined the data from 15 RCTs to evaluate the impact of cognitive stimulation on people with dementia. The authors concluded that there was consistent evidence from multiple trials that cognitive stimulation programmes benefit cognition in people with mild and moderate dementia over and above any medication effects. The findings suggested that cognitive stimulation has a beneficial effect on the memory and thinking test scores of people with dementia. The review also showed that cognitive stimulation improved communication, social interaction and quality of life for people with dementia. However, the authors noted the variable quality of the trials and small sample sizes, as well as urging further research on the potential long-term benefits of cognitive stimulation and their clinical significance.

While cognitive stimulation has proven effective, once therapy is concluded it is unclear just how long the benefits last (Woods et al, 2012). It is important to remember that dementia is associated with progressive cognitive decline. This,

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coupled with the fact people are diagnosed at different ages and at different stages of the disease, makes it difficult to pinpoint how long such treatment can be deemed successful. Quality of life may improve, but further improvements in cognition may be limited because of the nature of the condition. Evidence in relation to the effectiveness of cognitive stimulation on family caregiver outcome measures is also not conclusive. The Cochrane Review only sourced three studies reporting on family caregivers outcomes (Spector et al, 2001; Onder et al, 2005; Bottino et al, 2005). No differences were noted between intervention and control groups; the effect sizes for anxiety, depression and caregiver burden were close to zero, indicating no likely differences in caregiver outcomes. That said, there was no evidence either that cognitive stimulation impacted negatively on caregivers. Not surprisingly, care is needed in interpreting the results for caregivers, given the small number of studies in the area and the variability in design, scale and scope of the published material.

Cognitive stimulation therapy (CST) is a particular form of cognitive stimulation and uses the evidence from reality orientation as a basis for further development, incorporating the positive aspects of the treatment whilst ensuring that the stimulation is implemented in a sensitive, respectful and person-centred manner (Woods, 2012). Unlike reality orientation, which attracted criticism due to its rigid, sometimes confrontational approach, CST has adopted a person-centred care approach to the delivery of the programme. There a number of principles that must be incorporated into CST sessions for the most efficient outcomes to be achieved. Principles include: mental stimulation, opinions rather than facts, triggers to aid recall, continuity and consistency between sessions, engagement and involvement, inclusion and fun (CSTdementia, 2017).

A typical session of CST lasts for one hour with a total of 14 themed sessions, usually provided over the course of seven weeks. Sessions generally follow the same warm up activity, a reality orientation board that contains information about the group and, in the case of Sonas in Ireland, a 'theme song' (Sonasapc, 2017). By following a

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standard structure, consistency in the sessions is enhanced leading to a more optimal learning experience for participants. The main topic or theme for the session is explored using as many senses as possible. Themes include: physical games, sound, current affairs, word association, using money and number games as well as practical activities including baking and gardening. As CST is usually implemented in a group setting, it also contributes a strong social element to the activity. People with dementia can sometimes feel isolated so any intervention that enables interaction among participants can lead to an improvement in confidence and social skills.

An initial trial of CST was conducted in 2003 (Spector et al, 2003) to test the hypothesis that the therapy would benefit cognition and quality of life for people with dementia. A total of 115 people were randomised to the CST intervention group and 86 to the control group. The results concluded that CST was effective, as those who took part had significantly higher scores on MMSE and ADAS-Cog and rated their quality of life (QoL-AD) more positively than the control group (Spector et al, 2003). The success of the trial led to a manual and training DVD being published in 2006. Since then, CST has continued to grow in popularity and is now used worldwide.

There is now good evidence on the effects of CST on different areas of cognitive function for people with dementia (Spector et al, 2010). The latter used ADAS-Cog to explore whether certain areas of cognition are more susceptible to the use of CST than others. Memory and new learning, language and praxis were broken into subsections of the ADAS-Cog, covering items such as word recall, naming, commands, word recognition and spoken language. Two items in particular, commands and spoken language, favoured the CST intervention group over the control group. CST appears to have particular effects in promoting language function, which is likely to lead to generalised benefits. Any improvement in spoken language is likely to aid communication and conversation, allowing the person with dementia to give their own opinion, thus impacting positively on their well-being.

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Aguirre et al (2012) carried out a study to investigate the characteristics which predict the best response to CST. A total of 272 participants took part in CST for 7 weeks. Respondent effects were measured using the ADAS-Cog, MMSE, DEMQoL and NPI for behavioural disturbances. A linear model was used to explore the impact of respondent characteristics on outcomes. The benefits of CST were independent of whether people were taking acetylcholinesterase inhibitor (AChEI) medication. The analysis showed that age and gender were two variables impacting on the effectiveness of CST. Older participants (over the age of 80) appeared to benefit more in relation to MMSE and ADAS-Cog. Greater improvements in ADAS-Cog were also more likely to be found in female participants over males. The living situation of participants appeared to affect results; care home residents improved more than community residents on quality of life, but the community sample seemed to benefit more in relation to behaviour problems. The results suggest that care must be taken when designing CST so that the programme of activities match the age, gender and location of participants.

Although cognitive stimulation therapy is often described as a brief therapy, maintenance cognitive stimulation therapy has also been explored extending beyond the initial 14 sessions. Maintenance cognitive stimulation therapy can be effective when compared to short-term cognitive stimulation, depending on outcomes observed (Orrell et al, 2014). The latter conducted a single-blind, multicentre, pragmatic, RCT and found improvements in both quality of life and proxy-related quality of life. The RCT did not find any significant changes in cognition. All participants completed a 45 minute session twice a week for 7 weeks. Upon completion, participants were then randomised into either a maintenance CST group for a further 24 weeks or control group with care as usual. At 3 months there was no significant difference in primary outcomes cognition (ADAS-Cog) or quality of life (QoL-AD). Secondary outcome proxy-related quality of life and activities of daily life scored higher for the maintenance group than the control group. Self-rated quality of life was higher and statistically significant at the 6 month primary endpoint for the

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maintenance CST group, although there was still no significant difference in cognition.

Cognitive stimulation therapy is usually conducted in small groups of about 5 to 8 people. However, many people still do not participate in group cognitive stimulation therapy. This may be because they do not want to leave their house, or restricted mobility or health issues prevent them from getting out, or they choose not to participate in group-based activities or groups may not be running in their local area (Orrell, 2012). In such circumstances, CST can be implemented on a one-to-one basis by the caregiver of the person with dementia in their own home. Providing individual cognitive stimulation, iCST, as opposed to group cognitive stimulation therapy has made it possible for more people to access the service. The concept of iCST has been well received by both carers and the person with dementia (Yates et al, 2015).

Orgeta et al (2015) conducted the first RCT of an individual, carer-led cognitive stimulation intervention. The aim was to evaluate the effects on cognition and quality of life among people with dementia and their carers. 356 participants were assigned either to the intervention group or care as usual. The results found no support for a home-based CST programme. There was no evidence that iCST reduced behavioural and psychological or depressive symptoms or increased activities of daily living for people with dementia. Neither were there any differences in carers' mood, resilience or relationship quality with the person with dementia. These findings may be due to compliance issues such as carers fitting iCST into their timetable, the lack of stimulation for some participants and difficulties reported by carers in engaging in the intervention (Orgeta et al, 2015). However, people with dementia did report improvements in relationship quality with their family carer; more sessions completed by the person with dementia, the greater the gains in carer relationship. This is consistent with the idea that meaningful activities conducted alongside family carers can strengthen the caregiving relationship. Carer's health-related quality of life

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ratings increased at the primary end point providing evidence that carer involvement can increase well-being in carers.

A more recent study by Orrell et al (2017) reported similar findings. They implemented a home based individual cognitive stimulation therapy. The RCT evaluated its effectiveness on primary outcomes of cognition and quality of life for the person with dementia and general health status of the carer and secondary outcomes incorporating the quality of the caregiving relationship and caregiver quality of life. A total of 365 people were divided into a treatment group who received iCST for thirty minutes, 2 to 3 times a week for 25 weeks and a control arm who received treatment as usual. No difference was found in primary outcomes of cognition and quality of life for the person with dementia or well-being of the carer, although the quality of life of the carer increased. Caregiving relationship improved from the perspective of the person with dementia. The number of sessions completed influenced the quality of the relationship as well as improvements in depression among carers. The social setting and additional stimulation of group CST may explain the differences in outcomes between group and individual sessions.

Cognitive stimulation therapy has also been evaluated in conjunction with medication. According to the Department of Health (UK), the evidence on pharmacological interventions alone suggests that these drugs appear to have only a limited positive effect in treating these symptoms but can cause significant harm to people with dementia (Department of Health, 2009). Antipsychotics are often the first port of call in the treatment of behavioural symptoms, but these drugs can have dangerous side effects. They are not particularly effective for management of neuropsychiatric symptoms such as apathy (Buettner, 2011). On the other hand, combining CST and pharmacological treatments have been noted to stabilize and improve cognitive functioning (Nui et al, 2010). Further evidence has confirmed the advantages of acetylcholinesterase inhibitors (AChELs) alongside CST (Orrell et al., 2014). Cognitive functioning with maintenance CST is enhanced when combined with

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the use of AChELs (Matsuda, 2007). While antipsychotics are not suitable for everyone, it is worthwhile noting their potential positive effect for some people when used in conjunction with a non-pharmacological intervention such as CST.

While studies have shown the benefits from using CST for improvements in cognition and quality of life, few have explored cost-effectiveness issues. Improving cognitive functioning can potentially delay the progression of dementia, in turn reducing the utilisation of hospital resources, long-term care and day care facilities. Knapp et al (2006) is one of a small number of studies to undertake cost effectiveness analysis as part of an RCT in this area. A total of 91 people with dementia, living in care homes or in the community, received a CST group intervention twice weekly for 8 weeks; 70 participants with dementia received treatment as usual. Service use was recorded 8 weeks before and during the 8-week intervention and costs were calculated. Costs were found to be no different between the intervention and control group. Outcomes were better however for the CST intervention group. To deal with uncertainty, cost-effectiveness acceptability curves were plotted. Overall, there was a high probability that CST was more cost-effective than treatment as usual, with regard to both quality of life and cognition outcomes. This led to the conclusion that CST has effectiveness advantages over, and may be more cost-effective than, treatment as usual.

An economic evaluation carried out by D'Amico et al (2015) examined whether group-based maintenance cognitive stimulation therapy (MCST) is cost-effective when compared to standard therapy. Participants were divided into an intervention group, who received 24 weeks of MCST and usual care or control group, who received care as usual. Primary outcomes were cognition (ADAS-Cog) and quality of life (QoL-AD). Although outcome gains were modest over 6 months, maintenance CST appeared cost-effective when looking at self-rated quality of life as primary outcome, and cognition (MMSE) and proxy-rated quality-adjusted life years as secondary outcomes. CST in combination with AChELs offered cost-effectiveness gains when

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outcome was measured as cognition. Continuation of CST is, therefore, likely to be cost-effective for people with mild to moderate dementia.

The evidence on the effect of CST on the caregivers of people with dementia is far less robust. A recent study by Aguirre et al (2014) suggests that CST seems to have a relatively specific benefit for people with dementia, but that any benefits that accrue may not carry over to family carers. Eighty-five family caregivers of people with dementia took part in their study. All the people with dementia received the standard twice weekly seven weeks of the CST intervention plus either 24 weeks of a maintenance CST (MCST) intervention or 24 weeks of treatment as usual. There was no evidence of any benefit in relation to family caregiver outcome measures, or any significant differences between intervention and control caregiver groups for any of the variables considered at any time point (3 and 6 month follow up). Caution is needed when interpreting the results given the relatively small numbers in the study and much more evidence is needed on the impact of different types of CST on caregivers providing care in different circumstances and locations before any firm conclusions can be drawn.

From reviewing the evidence on CST, it is clear that significant benefits can be achieved from using it, including potential cost effectiveness gains, in the treatment of dementia. CST for people with dementia is the only non-medical therapy endorsed by UK government NICE guidelines for cognitive symptoms and maintaining function in dementia. NICE recommends the use of group cognitive stimulation as a form of dementia management, regardless of drug treatment. Specifically, the guidelines suggest that “people with mild to moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health social care staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive stimulation of dementia” (NICE, 2006). NICE guidance also emphasised a need for more research in to the clinical and cost-effectiveness of

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cognitive stimulation therapy in combination with and comparison to anti-dementia drugs such as acetylcholinesterase inhibitors (ACHEIs). In addition, the 2011 World Alzheimer Report (Prince et al., 2011) concluded that *'there is strong evidence to support cognitive stimulation programmes and these interventions should therefore be routinely offered'*.

Traditionally, cognitive interventions have focused on attempts to improve non-specific stimulation in thinking, concentration, memory and other cognitive functions normally associated with early stage dementia. Relatively little attention has been given to developing psychosocial interventions aimed at helping people with dementia achieve specific goals in day to day life. A cognitive impairment causes problems with thinking and concentration, which can limit engagement in activities and lead to anxiety, depression or restrictions in social participation. These are examples of excess disability caused by cognitive impairment within dementia (Bahar-Fuchs, 2013). By targeting difficulties deemed most relevant, individuals can use their retained strengths, reflected in preserved aspects of memory, to enhance self-efficacy, coping and well-being, thereby minimising excess disability.

Cognitive rehabilitation refers to an individual approach of improving functioning in the everyday context rather than enhancing performance on general cognitive tasks (Bahar-Fuchs et al, 2013). People with dementia and their carers work together with a health professional over a number of sessions to identify personally relevant goals and devise and implement strategies for achieving these. These goals may include: remembering what happened yesterday and reducing repetitive questioning or remembering the names of people you meet (memory), remembering what you were doing before getting distracted (concentration) or improving use of a calendar to remember non-routine events (organisation) (Clare et al, 2013).

Generally speaking, there is a lot of individual variability in how people respond to different strategies. Due to the diverse range of needs and circumstances, it is

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preferable to try several strategies in an attempt to determine what works best for each individual. These strategies may focus on taking in and remembering information. This could be done through linking stories to information (mnemonics), grouping information into categories (chunking), or associating information with a specific location (method of loci). Other strategies include cueing or spaced retrieval (Kelly, 2015). The person's intrinsic capacity may be enhanced by additional resources such as memory aids or environmental adaptation.

Unfortunately, there is limited evidence available to make definitive judgements on the effectiveness of cognitive rehabilitation for people with dementia. A Cochrane systematic review was conducted in 2013 on cognitive training and rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. Only one RCT on cognitive rehabilitation was sourced in this review. The study compared individual, goal-oriented cognitive rehabilitation with relaxation therapy to a no-treatment control group (Clare et al, 2010). The study involved 69 individuals, the majority of whom lived at home with family. The intervention used practical aids and strategies, techniques for learning new information, practice in maintaining attention and concentration and techniques for stress management in order to achieve their personal goals. These were practiced between sessions. The intervention consisted of eight, 60 minute sessions, conducted on a weekly basis in participants' homes. Cognitive rehabilitation was found to be superior in the short-term to usual care in relation to the primary outcome of patient-reported improvement in goal performance. Participants also rated themselves as more satisfied with their ability to carry out meaningful activities of daily living.

Since then, Kim (2015) conducted a study to investigate the effect of cognitive rehabilitation on performance of everyday activities. The study also incorporated the use of cognitive training into the intervention. Forty-three people who were diagnosed with Alzheimer's disease participated in the study; 22 people were randomly assigned to the cognitive stimulation group and 21 to the control group.

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The intervention consisted of 8 sessions. Each session lasted 60 minutes (30-minute group session, 30 minutes' individual session) and took place 1 day per week. The control group received unstructured conversation and questioning as well as health-related videos once a week. Each participant used strategies to achieve personal goals in the individual sessions while the groups used cognitive training tasks. This included the use of a calendar and personal memory notebook. The results indicated that improvements were achieved in relation to performance and satisfaction, QoL and the MMSE orientation subscale, while significant differences in these outcomes between the two groups in favour of the intervention were also noted. These results were consistent with Clare et al (2010) where a strong correlation between performance and satisfaction was also reported.

Although cognitive rehabilitation is conducted with a healthcare professional, there is a requirement of commitment and effort on the part of the person with dementia to practice implementation between each session. This can be a limitation as it is time consuming for the participants and their family carers and may result in commitment issues. It was also noted by Choi et al (2013) that a certain number of neuropsychological and psychological obstacles may prevent engagement in cognitive rehabilitation among people with Alzheimer's disease. Denial, depression/hopelessness, defeatist beliefs or increasing cognitive deficits may hinder the individuals' participation and chances of cognitive rehabilitation being effective. Due to these factors, patients must be adequately motivated to participate consistently for the treatment to be fully beneficial.

Despite these constraints, cognitive rehabilitation has the potential to be a valuable intervention, especially for people in the early stages of cognitive impairment who still have the ability to retain or learn new information. Its individual approach allows people to have as much control over their daily life as possible. It enables the person to maintain functioning, engagement and participation in their day to day lives. Cognitive rehabilitation also gives a person with dementia the chance to achieve goals that are important to them. Therefore, rehabilitation can be genuinely person

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centred, reflecting important values underpinning good dementia care (Clare, 2017). However, research to date has been hampered by small, underpowered studies and a lack of randomised controlled trials (Choi, 2009). There is a clear need for well-designed studies with larger samples to obtain more definitive evidence on the potential of cognitive rehabilitation in dementia (Bahar-Fuchs, 2013; Boudreaux, 2011).

One such recent trial is the Goal-oriented Cognitive Rehabilitation in Early-stage Alzheimer's and Related Dementias: Multi-centre Single-blind Randomised Controlled Trial (GREAT) trial involving 475 people across eight sites in England and Wales. Half of participants received ten cognitive rehabilitation sessions over three months, and the other half did not. The group receiving the therapy then took part in four "top-up" sessions over six months. Early results from this trial suggest that personalised cognitive rehabilitation therapy can help people with early stage dementia significantly improve their ability to engage in important everyday activities and tasks. Cognitive rehabilitation enabled people with dementia to maintain their functioning and independence in relation to task-based activities, security and social connection (Clare et al, 2017).

A recently reported ongoing randomized controlled trial focuses on the implementation of a cognitive behavioural treatment (CBT) programme for people with dementia, caregivers and the dyad relationship, consisting of 8 modules and 25 sessions (Forstmeier et al, 2015). The trial has the potential to provide evidence for the development of future guidelines for the psychological treatment of people with dementia and their caregivers. Similarly, a recent pilot study of cognitive behavioural therapy for anxiety in dementia showed that the methodology was both feasible and effective, with significant improvements in depression, but that a fully powered RCT was now required (Spector et al, 2015).

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## 6. Psycho-Educational Interventions for Carers

Carers play a pivotal role in the lives of people with dementia. Throughout the world, it is family members who tend to take on the responsibility of the primary caregiver (Family Caregiver Alliance, 2011). Females take up the role of the carer more often compared to men. Internationally, around two out of three primary carers are female (Global Alzheimer's and Dementia Action Alliance, 2017). Currently, in Ireland there are approximately 50,000 carers, of whom the majority are female (Alzheimer Society of Ireland, 2015). Carers undertake a wide range of responsibilities, which can differ depending on the stage of the disease. The roles of a caregiver for a person with dementia normally include personal care, transportation, shopping, financial help, plus all other required services (Kajiyama et al, 2013). Dementia is a challenging journey as the needs of the person with dementia are ever changing. Quinn et al, (2008) identified four main themes associated with caring for people with dementia: difficulties understanding the nature and meaning of the diagnosis; changes in the relationship; problems and challenges; and ways of coping with the disease. The key message was the carers need for guidance and support when it comes to dealing with a dementia diagnosis.

The provision of a high standard of dementia care requires caregivers to acquire the knowledge and skills needed to deal with changing needs. Not surprisingly, the role of caregiver puts pressure on the carer, both physically and emotionally. The amount of time spent caregiving also leaves little room for carers to attend to their well-being and needs. Carers report high levels of burden and psychological morbidity, as well as social isolation, physical ill-health and financial hardship (Bordaty& Donkin, 2009). Stress in caregivers is especially associated with the negative effects of dementia such as agitation and behavioural problems. An increase in stress levels can, in turn, have

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a negative impact on caregivers' mental health. As well as access to emotional support, recognition of their own health needs is essential (NICE-SCIE, 2006).

Psycho-educational interventions can alleviate some of the pressure and strain inherent in the caring relationship. These range from specialized educational classes involving skills training, to peer support programs, to different types of counselling programs (Fortinsky, 2009). Carer training, such as learning how to manage dementia symptoms, coping skills and enhancing knowledge, along with counselling have been specifically evidenced as effective (Peacock and Forbes, 2003; Sorensen et al, 2006). Evidence from systematic reviews suggest that psycho-educational interventions can help to reduce burden, enhance emotional well-being and reduce depression and anxiety (Acton and Kang, 2001; Brodaty et al, 2003). While much of the evidence relates to psycho-educational interventions for carers of people with moderate or late stage dementia, there is also interest in early stage supports (Clarke et al, 2003). The World Health Organisation recommends that psycho-educational interventions should be offered to family and other informal carers of people with dementia at the time when diagnosis is made (WHO, 2012). Similarly, the Dementia UK report (Alzheimer Society, 2007) recommends carer support packages and, in particular, psychological therapies that include carer training and support groups.

Milne et al (2014) evaluated a local, multi-component, psycho-educational support programme for carers in Medway in Kent in England. They conducted a comprehensive evaluation of seven Carers Courses targeted at the carers of people who had received a recent diagnosis of dementia. The courses were developed in response to the growing recognition of the value of interventions that focus on both the person with dementia and their relatives. Courses were offered upon diagnosis or at the end of a post-diagnostic counselling meeting. They were made up of 10 sessions in which speakers from a number of areas presented on topics such as: accessing social services support, communication and dementia, coping strategies and managing challenging behaviours, among others. The authors noted multiple

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positive outcomes associated with these courses, including psychological support, enhanced coping skills, enhanced confidence, increased knowledge and preparation for the future. Findings also showed participants benefitted from the emotional support arising meeting other carers.

A RCT conducted by Gavrilova et al (2009) found a reduction in carer burden from the application of an education and training intervention for caregivers in Russia. Carers from 60 families were randomised to receive either the intervention and medical care or medical care as usual. The intervention comprised weekly half hour sessions, delivered by newly qualified doctors, completed over the course of 5 weeks. The intervention focused on: assessment; basic education about dementia; and training on specific problem behaviours in dementia. Caregivers in the intervention group reported large and statistically significant net improvements at 6-month follow-up in caregiver burden compared to controls. There were no differences in relation to caregiver psychological distress and patient and caregiver quality of life.

Dias et al (2008) evaluated the effectiveness of a home care program delivered by a community team comprised of two full-time Home Care Advisors and a part-time local psychiatrist who visited carers at home at least once a fortnight. Components involved basic education about dementia, knowledge about behaviour problems, support for caregivers, networking of families and advice regarding government schemes. Outcomes were assessed after 3 and 6 months. The main findings showed significant improvements in caregiver mental health and burden following the intervention. Reductions in behavioural disturbances, functional ability and risk of death were also found, although none of these were statistically significant. The authors noted the limitation of a small sample size which may have reduced the power to detect behaviour problem reductions.

Jensen et al (2015) completed a systematic review and meta-analysis of randomised trials on the effectiveness of educational interventions for informal caregivers of

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people with dementia residing in the community. They screened 1,390 citations and included 7 RCTs with 764 participants. Meta-analysis of 5 trials showed a moderate effect on carer burden. Meta-analysis of 2 trials showed a small effect on depression. There was no effect on the number of transitions to long-stay care. Effect on quality of life was not estimable as studies varied in reporting sub-domains and constructs within scales.

Telephone-based supports can potentially provide a low cost, low burden, emotional support alternative to face-to-face interventions (Finkel et al, 2007). Positive effects were found in studies which combined telephone based support with in-home sessions. Elliot et al (2010) reported the results from the REACH II study which aimed to reduce stress and burden in caregivers. It comprised of three computerised telephone support sessions along with nine educational materials on self-care and a “health passport” providing information on health maintenance. They randomly assigned 495 dyads to either intervention or control to determine the benefits of a structured, multi-component skills training intervention. At the six month follow up, carers in the intervention reported better self-reported health, improved sleep quality, and better physical and emotional health. Nichols et al (2011) based their study on the REACH II trial. Their six-month REACH VA study incorporated nine individual in-home sessions and five one-hour group telephone support sessions into a caregiving training intervention. They achieved outcomes similar to the REACH II trial, reporting improvements in caregiver burden, depression, health and self-care and social support. Other significant findings included improvements in management of patients’ behaviours and a two-hour decrease in caregiving hours per day.

The European Skills training and Reskilling (STAR) project which ran from 2010-2014 aimed to provide effective care to dementia caregivers. The project involving six countries: the Netherlands, Sweden, Italy, Malta, Romania and the UK, developed a web-based training portal for informal as well as formal caregivers. International dementia experts composed content into eight modules, comprising basic,

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intermediate and advanced levels. Participants also had access to information and support from online community of peers and experts. The control group has free access to the intervention once the trail was completed. Primary outcomes included: overall usefulness, user friendliness and impact on knowledge, as well as the impact on empathy, attitudes and a sense of competence (Hattink et al, 2015). Data was collected after two to four months. Participants rated each module. Modules found to be most useful were those dealing with difficulties in daily life and those showing how to help and provide support strategies for coping with dementia consequences. Empathy also improved showing an increase in the level of understanding towards people with dementia. Subsequent studies on web-based interventions mirrored these results and found improvements in its usefulness and convenience (Lewis et al, 2010) and in carer knowledge and attitudes (Irvine et al, 2012).

Stress, depression and quality of life were evaluated using an online iCare stress management e-training program for caregivers (Kajiyama et al, 2014). Caregivers were assigned to receive either the training program or information and education only. The training program was modified from an evidence based treatment “coping with caregiving” by Gallagher-Thompson (2003) and adapted for online use. The intervention comprised of seven modules including information on dementia and segments on specific skills in dealing with dementia. Caregivers also filled out a workbook at the end of each module. 150 participants were enrolled in the study and completed a questionnaire at baseline and again at the end of the three-month time period in terms of how often they used the program and its usefulness. Results from these questionnaires showed that caregivers in the intervention group experienced greater reductions in stress compared to the control. Overall, the iCare management program increased the carers’ ability to handle common caregiving situations more effectively.

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Communication is a key aspect in carers' ability to understand the needs of the person with dementia. Moreover, a high level of communication can also facilitate person-centred care (Edvardsson, 2010). As the decline in memory and thinking occurs, the person with dementia may become withdrawn as they are no longer able to express themselves. This isolation reduces the persons' ability to effectively communicate with their caregiver, who can find themselves solely leading and supporting any interaction. A lack of understanding can lead to a breakdown in communication causing stress on both sides of the caregiving relationship. In order to combat this, Liddle et al (2012) used memory and communication strategies to develop a training DVD for caregivers. Twenty-nine dyads were included in the study and were allocated either the MESSAGE (communication) and RECAPS (memory) training. The intervention showed a significant improvement in carer's knowledge of communication strategies and carers reported a high level of satisfaction, finding the training useful. However, there was no impact on the quality of life of people with dementia as measured by the Cornell Scale for Depression in Dementia.

Haberstroh et al (2011) also developed a communication training program based on the TANDEM model. It aimed to enhance the quality of life of people with dementia along with reducing burden in caregivers by developing caregivers' communication skills. Carers underwent five two and half hour sessions weekly, which combined theoretical concepts and skills training. Each session follows a new topic and the participants exchange experiences from the previous session, allowing them to learn from each other. Case studies and role play were also involved. Caregiver mood was recorded in diaries and quality of life in the person with dementia was measured using caregiver proxy reports. The results from the intervention found that the quality of life for the person with dementia was significantly improved in comparison to control group. However, there was no effect on caregiver burden.

As part of psycho-educational interventions, counselling has been shown to reduce the risk of depression in carers (Mittleman et al, 2004). Caregivers were randomly

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assigned to either a group receiving enhanced counselling and support treatment or a group receiving usual care (control group). Caregivers in the enhanced treatment group were provided with six sessions of individual and family counselling, agreed to join support groups 4 months after enrolment, and received on-going ad-hoc counselling. The Geriatric Depression Scale was administered at baseline and at regular follow-up intervals for as long as the caregiver participated in the study. After baseline differences were controlled for, caregivers in the enhanced treatment group had significantly fewer depressive symptoms after the intervention than participants in the control group. These effects were sustained for three years after baseline; they were similar across gender and patient severity level and were sustained after nursing home placement or death of the patient.

Sorensen et al (2008) examined the impact of an intensive structured psychosocial intervention programme involving tailored counselling, education and support groups for people with mild Alzheimer's disease and their spouse carers. The analysis revealed that people with dementia found support groups relevant: they found it stimulating to be with peers, it supported their self-esteem, and it supported them in finding new ways of managing everyday life and social relations. During and after the intervention, caregivers were better able to cope with the challenges their partner's disease involved, and they were able to face everyday life and social relations with higher levels of confidence and competence. After the intervention, both patients and caregivers sought suitable support groups they could join as a permanent activity and caregivers sought permanent counselling. Although small in scale, the study indicates that tailored counselling and support may improve outcomes for people with dementia and their carers.

Psycho-educational interventions for caregivers have demonstrated their ability to be clinically effective. Their effectiveness can also translate into savings for the health sector. Adequate, timely education and training can improve the quality of life for carers' and people with dementia. In turn, this often delays the transition into care

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homes. According to Gaugler et al (2005), early provision of in-home education support decreases the risk of institutionalisation by 22%. A support programme at the time of diagnosis aimed at caregivers reported a reduction of care home placement by 28% (Banerjee et al, 2007). Investing in training and supports which enable carers to provide an effective level of care will keep people with dementia living well in the community for as long as possible. Telephone and internet based interventions may also lower the cost of care, as they eliminate the need for health care professionals and caregivers to travel to provide supports (Finkel et al, 2007).

A study by Mittelman et al (2006) conducted a randomized controlled trial of an enhanced counselling and support intervention for caregivers of people with dementia compared to usual care. The intervention consisted of six sessions of individual and family counselling, support group participation, and continuous availability of ad hoc telephone counselling. Follow-up intervals were every 4 months for the first year and every 6 months thereafter. Cox proportional hazard models were used to test the effects of the intervention on the time to nursing home placement for the patients after controlling for multiple time-invariant and time-dependent predictors of placement. People with dementia whose spouses received the intervention experienced a 28% reduction in the rate of nursing home placement compared with usual care controls. The difference in model-predicted median time to placement was 557 days. Improvements in caregivers' satisfaction with social support, response to patient behaviour problems, and symptoms of depression collectively accounted for 61% of the intervention's beneficial impact on placement. The resulting cost savings were not calculated but were likely to be significant.

There is emerging and consistent evidence to suggest that participating in psycho-educational interventions, incorporating skills training, peer support programmes, psychological therapies and counselling, has positive effects on caregivers of people with dementia. The National Collaborating Centre for Mental Health's 2007 review of qualitative evidence suggested that psycho-educational interventions can be effective in reducing the risk of depression and bolstering coping skills (Mason et al,

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2006) amongst carers if offered early in the dementia trajectory. The benefits of psycho-educational interventions are strongest where: the carer attends a separate group to that of their relative; support is tailored to the needs of a specific group of carers at a particular stage of caring; the intervention includes a combination of skill building, education and support; and it is easily accessible, low cost and time limited (Elvish et al., 2012; McHugh, et al 2012). While the quality of the evidence remains an issue, it is reasonable to say that practical educational supports for carers can impact on the quality of care of people with dementia and carer burden. The transition to long-stay care may be delayed, allowing the person with dementia to remain living at home for longer. While face-to-face interventions tend to yield the best results (Thompson et al, 2007), telephone and web-based interventions can also provide cost-effective solutions to caregiver time constraints. Therefore, psycho-educational interventions which seek to reduce stress, depression and feelings of isolation among carers through the development of coping skills and resilience may be worthwhile, as part of a comprehensive post-diagnostic support programme for people with dementia.

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## 7. Psychosocial Interventions

Psychosocial interventions have the potential to be an effective, alternative source of treatment for people newly diagnosed with early stage dementia and their carers'. A psychosocial intervention is a broad term used to describe different ways to support people to overcome challenges and maintain good mental health (The British Psychological Society, 2014). Psychosocial interventions play a multidimensional role in maintaining cognitive functioning and independence and reducing challenging behaviour and emotional distress. Focusing on these problem areas can help the person with dementia come to terms with their diagnosis and maintain a good quality of life for as long as possible. The fact that the term 'psycho-social intervention' incorporates a range of different service models and elements such as social activity, emotional support, and psychological therapy, makes evaluation difficult. Although there are many examples of good practice few interventions have been rigorously evaluated (Glendinning et al., 2009). There is also considerable inconsistency between study designs and methods in the studies that have been done preventing meaningful comparison and challenging the validity of the evidence base (Moniz-Cook et al., 2008).

The absence of a consistent body of evidence has not slowed the growing interest in the use of psychosocial interventions in dementia. The number of large-scale RCTs and systematic reviews in the area of psychosocial interventions has grown in the past twenty years, although the disparity between the number and quality of drug trials and psychosocial trials is still evident. The lack of robust and compelling evidence with regard to psychosocial interventions makes it difficult to be prescriptive with regard to best practice. Moreover, many psychosocial interventions are not commonly thought of as post-diagnostic supports for dementia. They are often directed at people in the later, more cognitively impaired, stages of

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dementia, including people living in nursing homes. However, dementia can be diagnosed at any stage of dementia and historically later diagnosis has been more common than early diagnosis. Hence, psychosocial interventions have the potential to be included within a post-diagnosis support programme for people with dementia, depending on the stage of diagnosis. In this chapter, we will concentrate on a small number of psychosocial interventions that have the potential to impact on the quality of life of people with dementia following diagnosis. Four of the most commonly referenced interventions are discussed: reminiscence therapy, life story work, music therapy and exercise.

### **Reminiscence**

Possibly the most popular and evidenced intervention in maintaining cognitive functioning and reducing behavioural problems and emotional distress for people with dementia is reminiscence. Reminiscence therapy involves remembering and recalling past memories and events from your life, often aided by looking at materials from a different time (The British Psychological Society, 2014). In most cases, reminiscence therapy is conducted as a time limited, small group process but can also be done in an individual setting (Okumura et al, 2008). The use of props such as old photos, music and personal belongings can elicit old memories and experiences and can help people with dementia maintain connections to past identities and roles, as well as providing a sense of comfort and security (Buse and Twigg, 2014).

People diagnosed with early-onset or mild to moderate dementia, who still have the ability to maintain cognitive functioning tend not to be the main focus of reminiscence therapy, which is often directed at those in the later stages of the disease, including those in long-stay care settings. For example, a recent large-scale study by O'Shea et al, (2014) reported gains from reminiscence in relation to the quality of life of residents with dementia living in nursing homes in Ireland. However, a study by Chung (2008) illustrated that psychological functioning in early stage dementia patients also improved after a three month reminiscence therapy

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intervention. These gains originated mainly from the enjoyment the participants got from the social aspect of the therapy. Reminiscence therapy allowed people with dementia to work on communication skills with the volunteers. Furthermore, Wang (2007) found that there was no significant differences in behaviour or activities of daily life within reminiscence groups between people with low cognitive impairment, and those with moderate dementia. This suggests that reminiscence can benefit people with mild dementia as well as people in later stages of the disease.

The evidence on the effectiveness of reminiscence for people with dementia is not generally convincing, mainly due to the small scale and poorly designed nature of existing studies. In the most recent Cochrane Review available (Woods et al, 2005), only four trials with a total of 144 participants had extractable data. The results were statistically significant for cognition (at follow-up), mood (at follow-up) and on a measure of general behavioural function (at the end of the intervention period). Care-giver strain showed a significant decrease for care-givers participating in groups with their relative with dementia, and staff knowledge of group members' backgrounds improved significantly. No harmful effects were identified on the outcome measures reported. Although the indications were promising, in view of the limited number and quality of studies, the variation in types of reminiscence work reported and the variation in results between studies, the review authors highlighted the urgent need for more and better designed trials so that more robust conclusions could be drawn.

There has not been an avalanche of well-designed trials since then, suggesting that we are still awaiting conclusive evidence on the benefits of reminiscence for people with dementia and family caregivers. A good example of a recent, well-designed and well-delivered trial is that of Woods et al (2016), but that work casts doubt on the effectiveness of joint reminiscence groups for people with dementia and their carers at various stages of the disease. Group facilitators received extensive training and followed a detailed manual to provide reminiscence activities for people with

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dementia and their carers. There were some benefits in terms of autobiographical memory, but here was no improvement in relation to primary outcomes, most notably on dementia-specific quality of life measure (QoL-AD). After 10 months, carers in the reminiscence groups reported higher anxiety on the GHQ sub-scale, while those allocated to usual treatment showed a reduced level of anxiety at this point.

The trial did not support the clinical effectiveness or cost-effectiveness of joint reminiscence groups. Possible beneficial effects for people with dementia who attend sessions as planned are offset by raised anxiety and stress in their carers. The lack of positive results is in contrast with the findings from the pilot trial platform for the study, where 12 weeks of joint reminiscence groups are associated with significant benefits to both autobiographical memory and to carer depression (Woods et al, 2012). The results are also not consistent with systematic reviews suggesting that involving people with dementia and carers together in an intervention leads to better outcomes for family care-givers (Brodaty et al, 2003). Nevertheless, the study shows that ambiguity still surrounds the effectiveness of reminiscence in the care of people with dementia.

### **Life Story Work**

Life story work (LSW), which is strongly related to reminiscence, may play a role in helping the person with dementia come to terms with their illness, enable the person retain their sense of identity and empower them to reflect on their achievements and accomplishments at a time when there may be feelings of loss or depression. Life story is an activity in which the person with dementia is supported by staff and family members to gather and review their past life events and build a personal biography. Garland and Garland (2001) describe life review as a highly structured form of reminiscence, which allows the participant to ascribe meaning and value to his/her life, and to come to terms with uncomfortable issues. A

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definition is provided by Woods, Spector, Jones, Orrell, and Davies (Woods et al, 2005): *life review typically involves individual sessions, in which the person is guided chronologically through life experiences, encouraged to evaluate them, and may produce a life story book*. A life review process then helps a person with dementia to recount and evaluate his or her life history in chronological order. The process can be represented in tangible form as a life story book, photo album, scrap book, memory box or memory book.

A recent systematic review covering five trials suggests that individual reminiscence work, using a life review or life story process, shows potential psychosocial benefits for people with dementia, although no benefits were seen with general reminiscence materials (Subramaniam & Woods, 2012). Benefits reported for life story include enhanced well-being (Lai et al, 2004); improvements in mood and some components of cognitive function (Haigh et al, 2006; Morgan & Woods, 2010); and reductions in disorientation and anxiety and improvements in self-esteem, memory and social interaction (Tabourne, 1995). The use of a life review process to develop a life story book appeared to be associated with the most positive results with people with dementia (Haight et al., 2006; Morgan & Woods, 2010) and the review concluded that this approach merits further exploration.

Life story books are now very popular in the dementia care field, and in 2011 in England, the Department of Health provided the funding to train 500 people to carry out life story work with people with dementia (see [www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk)). Life story books have the potential to act as a tangible self-reminder and help to maintain a sense of continuity for people with memory difficulties. Similarly to reminiscence therapy, life story is mainly directed at people in the moderate to later stage of dementia. However, the following studies show that it could form part of a post-diagnostic support framework.

An important feature of life story work, is its ability to uphold person-centred care. To demonstrate this, McKeown et al (2010) evaluated LSW in order to understand its

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development, how it is experienced by participants and how it affects delivery and outcomes in care. They conducted an RCT made up of four case studies. One such case study followed a woman in a social care resource centre which she attended for day care and respite. This choice of setting suggests that those with mild/moderate dementia attending day centres may benefit from life story work as much as people with advanced dementia. Through observing the process, interviews with family and staff members and maintaining a care plan and research diary, the authors showed that LSW helped in maintaining the personhood of the people with dementia. This was evident in the day centre as staff viewed the woman within the context of her life experiences, not just as a “patient”, which strengthened the care relationship.

The use of a life review process to develop a life story book is also associated with positive results in dementia. Subramaniam et al (2014) conducted an RCT on the use of life story books, in addition to life review sessions, for mild to moderate people with dementia in relation to quality of life, mood, autobiographical memory and care relationships. Trained therapists undertook 12 life reviews sessions with 11 participants about the different stages of their life, followed by a life story book. The intervention had positive results on quality of life and memory for participants relative to the control group.

A subsequent study by Ingersoll-Dayton et al (2013) recorded benefits for a couples’ life story approach where people with dementia worked alongside their spouse or partner. It focused on helping couples to communicate, reminisce about the story of their relationship and build a book that incorporates different memories. The findings show that couples clearly enjoyed both the process of collaboratively telling the story of their life together and reviewing the resulting Couples Life Story Book. Dyads were more likely to use words such as “we” and “partners” toward the end of the intervention, suggesting that this approach may help to enhance their view of themselves as a couple, leading to enhanced levels of coping as the disease progresses (Ingersoll-Dayton et al, 2013).

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## **Music Therapy**

Music therapy is another potentially valuable therapeutic approach and the most common form of arts therapy to aid dementia. Music Therapy Ireland, for example, suggest that music therapy can address underlying difficulties and provide strategies regardless of whether a diagnosis of dementia has been made or not. The evidence on music therapy is mainly confined to interventions in care homes. For example, Riddler et al (2013) explored the impact of individual-based music therapy on agitation among people with dementia living in nursing homes. The focus was on quality of life and medication outcomes. Participants were given six weeks of music therapy followed by six weeks of standard care. Agitation and disruptiveness increased during standard care, but decreased during the music therapy intervention. Medication increased more often during standard care compared to music therapy. Similar positive results in relation to agitation were found in a study by Lin et al (2011) which was also conducted in a nursing home facility.

Choi et al (2009) evaluated the use of a group-based music therapy for behavioural and psychological symptoms in people with dementia living in the community. Twenty people were non-randomly assigned to either a music group or care as usual. The music intervention took place for fifty minutes, three days a week over the course of five weeks. Music intervention involved singing songs, analysis of libretto, making musical instruments and playing instruments (Choi et al, 2009). Significant improvements were seen in the intervention group with regards to depression and general quality of life. There were also significant improvements in relation to behavioural disturbances, including less agitation and reduced carer distress.

Like many psychosocial interventions, music therapy groups are a social activity, which promote interaction and communication between participants. This contributes towards improving social skills and reducing the risk of isolation. Music

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taps into an individual's sense of self in relation to personal preferences and goes beyond the idea of music as a tool to fix behavioural problems. People with dementia attest to its mental stimulating effects, emotional meaningful experience, its link to their personal identity and its ability to build and sustain relationships with others (McDermot et al 2014).

Regardless of these positive-leaning results, it should be noted that a recent 2017 Cochrane review assessed the effects of music-based therapeutic interventions on emotional well-being, mood disturbance, behavioural problems, social behaviour and cognition for people with dementia (Van Der Steen, 2017). Sixteen studies with a total of 620 participants contributed data to meta-analyses. Participants in the studies had dementia of varying degrees of severity, but all were resident in institutions. Five studies delivered an individual music intervention; in the others, the intervention was delivered to groups of participants. The methodological quality of the studies varied; were at high risk of performance bias and some were at high risk of detection or other bias. The authors found low-quality evidence that music-based therapeutic interventions may have little or no effect on emotional well-being and quality of life, overall behaviour problems and cognition. There was moderate-quality evidence that music reduces depressive symptoms, but agitation or aggression was not reduced. The quality of the evidence on anxiety and social behaviour was very low, so effects were very uncertain. The evidence for all long-term outcomes was also of very low quality.

### **Exercise**

Exercise is generally seen to carry the potential to improve people's physical function, mental health and overall well-being. Exercise programs with older adults have also been shown to improve cognitive function (Angevaren 2008; Erickson 2011; Tseng 2011) and depression (Chen 2009). Hamer (2009) concluded that exercise is inversely associated with risk of dementia (i.e. reduces the likelihood of dementia) based on a systematic review that included 16 prospective studies (163,797 participants without dementia at baseline with 3219 with dementia at follow-up). Intlekofer and Cotman

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(2013) suggests that evidence is starting to emerge that exercise supports brain health, even when initiated after the appearance of AD pathology. Not surprisingly, exercise is among the potential protective lifestyle factors identified as a strategy for treating the symptoms of dementia or delaying its progression (Lautenschlager et al, 2010).

Exercise programmes for people with dementia can include a wide range of activities from simply walking across the room to more robust activities such as gardening and dancing. Research has consistently demonstrated that exercise has the potential to improve physical function in all types of settings (Hauer et al., 2012). Vreugdenhil et al (2012) also reported positive findings in physical function as part of their RCT of a community based exercise programme. Similarly, Steinburg et al (2009) designed a feasible and effective exercise intervention for a home setting. An exercise physiologist administered an exercise program to 27 participants. The daily exercise program consisted of three components; aerobic fitness, strength training and balance and flexibility training. The goal of the study was to improve functional performance. Secondary goals were to assess the effects on cognition, neuropsychiatric symptoms, quality of life and caregiver burden, as well as the safety and feasibility of the intervention. The results show improvements on measures of hand function and lower extremity strength. However, among the secondary outcomes, no benefits were noted.

There are very few studies on the economics of exercise programmes for people with dementia. D'Amico et al (2015) explored costs and outcomes within a two-arm, pragmatic, randomised, controlled, single-blind, parallel-group trial of a dyadic exercise regimen (individually tailored, for 20–30 min at least five times per week). The study randomised 131 community-dwelling individuals with dementia and clinically significant behavioural and psychological symptoms with a carer willing and able to participate in the exercise regimen; 52 dyads provided sufficient cost data for analyses. The exercise intervention was more cost-effective than treatment as usual from both societal and health and social care perspectives for the measure of

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behavioural and psychological symptoms (Neuropsychiatric Inventory). It does not appear cost-effective in terms of cost per quality-adjusted life year gain.

Unfortunately, the overall evidence on the impact of exercise in dementia is not compelling. Forbes et al (2015) undertook a Cochrane review of exercise programmes for people with dementia. They examined seventeen trials and found limited benefits for people with dementia following exercise. The included trials were heterogeneous in terms of subtype and severity of participants' dementia, and type, duration, and frequency of exercise. Only two trials included participants living at home. There was no clear evidence of benefit from exercise on cognitive functioning. Neither was there was no clear evidence of benefit from exercise on neuropsychiatric symptoms or quality of life. There was some evidence of benefit of exercise programs on the ability of people with dementia to perform ADLs. In one trial (Vreugdenhil, 2012), the burden experienced by informal caregivers providing care in the home may be reduced when they supervise the participation of the family member with dementia in an exercise program. There was no evidence that exercise was harmful for the participants in any of the trials. Overall, the authors judged the quality of evidence behind most of the results to be very low.

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## 8. Evidence Synthesis

Post-diagnostic support for people newly diagnosed with dementia is an important topic worldwide. People recently diagnosed with dementia do not always get the information and care they require in a timely matter. Similarly, carers are often left with little to no information on the disease or advice on the services available to them at this critical time. The aim of this report was to identify best practice in regards to post-diagnostic support for people with dementia, based on a review of the important research in the area and observations on what services and supports seem to work best across countries. The findings can be used by the National Dementia Office to inform the priority action area ‘Timely Diagnosis and Intervention’ as set out in the Irish National Dementia Strategy.

The vast majority of people with dementia in Ireland have never received a diagnosis; many of them do not know they have the disease. This makes it very difficult to talk about post-diagnostic support for this group of people who remain entirely disenfranchised from the formal care system. For some who have received a diagnosis, it may have come late, when the dementia has advanced to moderate or severe status. These people may need high levels of support straight away, including admission to long-stay care for some. The remainder of people tend to get a diagnosis in the early stages of the disease and these people have been the focus of this paper. Getting a diagnosis of dementia is not an endpoint in itself, but represents the start of a complex care pathway of ever-changing needs. But what happens in the early stages following a diagnosis can set the pattern for what it is to come, for both the person with dementia and their carer.

In Ireland, the diagnosis gap can be attributed to a number of factors. Stigma has consistently surrounded the disease here and in other countries. A lack of

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understanding and awareness of dementia can sometimes lead people to see it as a normal part of the aging process and therefore not worthy of special attention. People may avoid seeking out medical treatment when symptoms arise, delaying the chance of obtaining an early diagnosis, whether through stigma or lack of knowledge and information. General practitioners, although they are often the first point of contact, may also find it difficult to diagnosis a patient. They may miss a diagnosis, especially in people who develop early-onset dementia, given the relatively few cases they see each year. There may also have concerns about the negative impact a diagnosis of dementia might have on the person or their family, making it less likely sometimes that a diagnosis will be made. There may also be element of therapeutic and resource nihilism among medical decision-makers – a sense that even if a diagnosis is made it is unlikely to change anything since there is no cure at present and services are absent or weak in any case. Services across the country are fragmented and people in rural areas especially can find it difficult to get the care that they need.

Memory loss is a frightening experience. Once a person starts to develop cognitive impairment, this often leads to feelings of fear, sadness, anxiety or distress. There is a sense of hopelessness that nothing can be done to help. On the other hand, a diagnosis can come as a relief to some people as it brings with it a sense of certainty. The fear of the unknown can be put to rest once dementia has been confirmed and the person can begin to plan for their future care. Putting in place a care plan while the person still has their cognitive abilities intact gives a sense of control and independence, as well as facilitating the inclusion of the person with dementia in the decision-making process.

Following a diagnosis, the person with dementia requires both practical and emotional support from a number of sources, some internal to the family, most external and the responsibility of the HSE. Post-diagnostic support helps to facilitate a good quality of life for the person with dementia for as long as possible. The

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immediate needs of the person depend on the timing of diagnosis. Those who receive a diagnosis in the early stages of dementia have different needs to those who receive a diagnosis late on in the disease. This is especially true in subgroups of people with early-onset dementia or Down syndrome, who face unique challenges and have specialised needs following a diagnosis. The importance of sharing the diagnosis, and discussing the changes being experienced, is not recognised enough for people with a learning disability (Bakker et al, 2010). Therefore, it is important to target post-diagnostic support in dementia care for specific groups of people with the disease. Post-diagnostic support must also reflect the heterogeneity of the general dementia population; people have very different needs depending on their age, stage of disease and existing co-morbidities.

Although there is no cure for dementia, supports and interventions are available which can change the course of the disease, potentially improving overall well-being and quality of life. However, the evidence is limited on optimal approaches to post-diagnostic support for people with dementia. The overall quality of the evidence is variable and poor. There is support for information and advice, cognitive stimulation therapy and rehabilitation and psycho-educational interventions for carers but for the majority of interventions, further research is needed in order to provide definitive support on their effectiveness. There is tentative support for different types of psychosocial interventions, such as reminiscence, life story work, music and exercise, but the conclusion of Moniz-Cook and Manthorpe (2009) that *“there are few proven and internationally accepted evidenced-based psychosocial interventions for people with early stage dementia living in the community still resonates nearly ten years on.*

Accessing basic information is usually the first port of call when someone is diagnosed, through leaflets, websites, dementia advisors or peer to peer supports. Not knowing how or where to access services is a recurring problem in many countries. People do not know whom to turn to for information. Therefore, dementia advisors and link workers have been introduced in many countries, such as Scotland,

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England and France, with a brief to provide individualised information and signposting to services. It is clear that information matters, but as part of a scheduled, individualised care trajectory. Trials have not yet succeeded in identifying specificity in relation to the optimal type and content of information provided, but it must be part of a complex, multi-component programme for tackling dementia. That's why the Advisor or Link Worker is highly valued in the early stages – that person can provide reassurance that help is available and that mechanisms exist for people to access key services and supports at the right time.

The literature on cognitive stimulation therapy (CST) provides some of the strongest evidence in relation to optimal post-diagnostic support in dementia. CST is the only non-medical therapy endorsed by NICE guidelines for cognitive symptoms. A Cochrane systematic review concluded that CST benefits cognition above any medication effects (Woods et al, 2012). Improvements in spoken language and the added social element of a group setting increases the persons' quality of life (Spector, 2010). Even though it remains unclear how long the positive effects last, due to the progressive nature of the disease, the message is clear - CST works for many people with dementia and should be an important element of the post-diagnostic support framework in Ireland. Cognitive rehabilitation has also demonstrated its effectiveness in a number of studies (Bahar-Fuchs et al, 2013, Hamperstead et al 2012, Boudreaux et al 2011). The evidence suggests that cognitive rehabilitation can support people to achieve the everyday goals that matter to them. However, compared to CST, the evidence is not as compelling, with further research needed to establish it as an optimal support. It is still unclear whether stimulation and rehabilitation delays the transition of people with dementia into nursing homes by supporting them to live independently at home for longer. Integrating the therapy into practitioners routine work, so that more people can have access and are supported to live better lives with dementia will be an important step in keeping people living at home for longer.

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Dementia also affects the lives of caregivers. A diagnosis can be emotional for a caregiver and takes its toll on physical and mental health. The WHO has recommended that psycho-educational interventions are offered to carers at the time of diagnosis to counteract some of the potential negative effects of the diagnosis and the subsequent caring burden (WHO, 2012). Providing support and education can alleviate carer stress while improving carers understanding of dementia and their relationship with the person with dementia. Research conducted showed that psycho-educational support sessions enhanced confidence, coping skills, knowledge and preparation for the future (Milne et al, 2014). A reduction in carer burden was achieved by Gavrilova et al (2009) through the use of a specific training and education intervention.

Psychosocial interventions are usually thought of as an effective support for those with moderate or severe dementia. Evidence has shown that they have the potential to work well as part of a post-diagnostic support system, especially as a diagnosis may sometimes not be made until these interventions are more relevant. Reminiscence therapy uses props such as old photos to elicit memories and experiences, improving cognitive functioning. Chung (2008) found improvements resulting from reminiscence, while O' Shea et al., (2014) reported gains in quality of life for people in residential care, although Woods et al (2016) reported no gains from community-based group therapy. Overall, the evidence remains compromised by methodological failings in the small number of studies that have been done. Life story work can also be used as a post-diagnostic support, allowing a person to keep intact their sense of identity and reflect upon past achievements. Life review sessions, in conjunction with life story work, has, for example, been shown to be effective (Subramaniam et al 2014). Once again, however, the quality of the overall evidence in this area is far from compelling. Music therapy has only produced limited benefits in residential care settings (Riddler et al, 2013), though there have been reports of positive effects in relation to agitation (Lin et al, 2010) and carer distress (Choi et al, 2009). Research has shown on multiple occasions that exercise has the potential to improve cognitive

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functioning, as demonstrated by Hauer et al (2012) and Vreugdenhil et al (2012), but this has not transferred into real gains when evaluated through Cochrane Review (Van der Steen, 2017).

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## 9. Conclusion

The evidence presented in this study provides a base from which Ireland can begin to build an efficient model of post-diagnostic supports for dementia care. It provides guidelines for the National Dementia Office on what works best for people newly diagnosed with dementia. While the overall evidence available to us in the literature is neither convincing nor compelling, there is enough material to build credible and effective post-diagnostic support structures for people with dementia in Ireland. Once diagnosed, people with dementia and their carers seem to value and benefit from well-defined and focused information sets, including signposting towards relevant and localised supports. Dementia advisors, connectors, navigators, link workers and peer support services resonate positively with people with dementia and their family carers. People with dementia want to be connected with appropriate services and having someone specifically assigned to this role is both appropriate and valuable.

Education and training in relation to the disease itself and on how best to care also seems to matter for caregivers. Significant investment in psycho-educational programmes for caregivers can also lead to potential economic benefits resulting from less people with dementia being admitted to residential care. Cognitive stimulation therapy has a proven pedigree and is under-provided currently in Ireland relative to its potential impact on people with dementia. The evidence on other psychosocial interventions is mixed, but it has to be said that, on balance, reminiscence, music and exercise have potential to impact positively on the lives of people with dementia and should be encouraged, and subsequently evaluated, as part of a comprehensive support system.

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Regardless of age, or timing of the diagnosis, post-diagnosis supports for people with dementia should be personalised and localised. The needs of each individual are complex and change as the disease progresses. Post diagnostic support should enable the person with dementia and their carer to move confidently from diagnosis to the next stage of the disease. For most people, those needs will be mainly social in the first instance, but some people will have clinical or behavioural needs that must be addressed following diagnosis. Incorporating a range of different interventions which suit the needs of the person with dementia along the way, enables the person to choose what is best for them at any given time. This grants the person with dementia the dignity and respect they deserve and most importantly allows them to live well with dementia for as long as possible. It also points to the need to have consistency in relation to key personnel looking after people with dementia along the continuum of care. There will be important transitions along the journey, for example the handover from social care to clinical care, but these can be made easier if key named workers are available to smooth any problems or anxieties.

Post-diagnostic support should provide for the full integration of the person with dementia into the care system, facilitating an early attachment that is both liberating and reassuring for people with disease and their families. For that to happen, we need to support more timely diagnosis, followed by immediate access to a named contact person that will facilitate maximum inclusion and independence for the person newly diagnosed with dementia. It really does not matter what that person is called – connector, navigator, advisor, co-ordinator – but it does matter that the contact person is embedded in the care system, has the credibility and authority to act as an agent for the person with dementia within a well-defined geographical area and has the necessary communication skills to interact with clinical and other providers. Information and advice should be guaranteed, so too should be signposting and, ultimately, if required, referral to both medical and psychosocial services, based on an on-going assessment of need by the named contact person. Consideration should be given to developing a comprehensive role description, based

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on the learning and evidence so far, so that one role is put in place rather than multiple roles carrying out different functions. A single comprehensive role would eliminate the need for the person with dementia to transition between different people with different skills and functions and would eliminate the corresponding need for more coordination on the part of the services.

Cognitive stimulation for people with dementia should form part of any initial post-diagnostic support structure, as should education and training for carers. Cognitive rehabilitation also has potential to be of significant benefit to people with dementia, although the quality of the evidence is not as robust as for stimulation. The evidence on other forms of psychosocial supports is weaker, mainly due to the quality of existing studies, but exercise, reminiscence and music therapies are worth exploring as part of an overall bio-psychosocial model of care. Ongoing evaluation in relation to both costs and effectiveness should form part of any new investment in post-diagnostic support for people with dementia. But we know enough about what works elsewhere to begin immediately the process of creating a comprehensive set of meaningful supports for all those recently diagnosed with dementia wherever they live and at whatever stage of the disease diagnosis occurs.

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