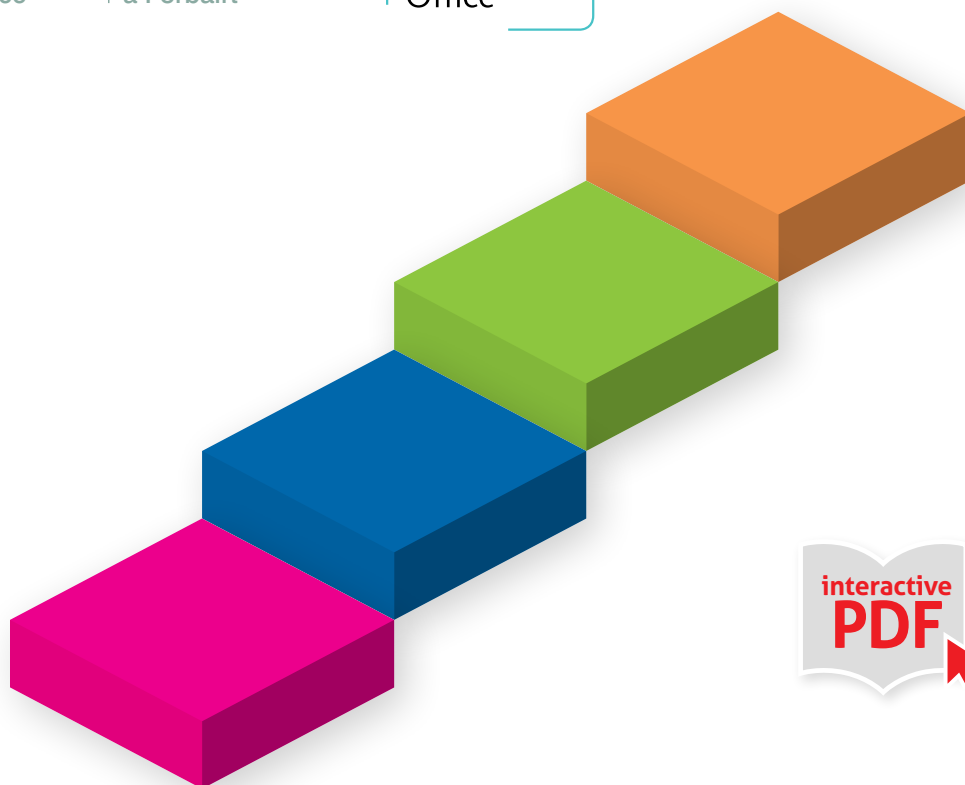




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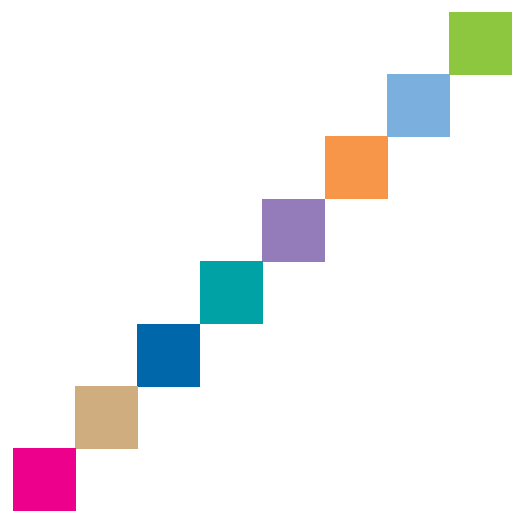
## Dementia post-diagnostic support guidance

Essential information for health  
and social care professionals



DEMENTIA SERVICES  
INFORMATION AND  
DEVELOPMENT CENTRE

*promoting excellence  
in dementia care*



This report was written by Matthew Gibb, Dearbhla O’Caheny, Cecilia Craig and Dr Emer Begley, with significant contributions from Lorraine Lovely, Margo O’Neill and Diana Burgui Murua.

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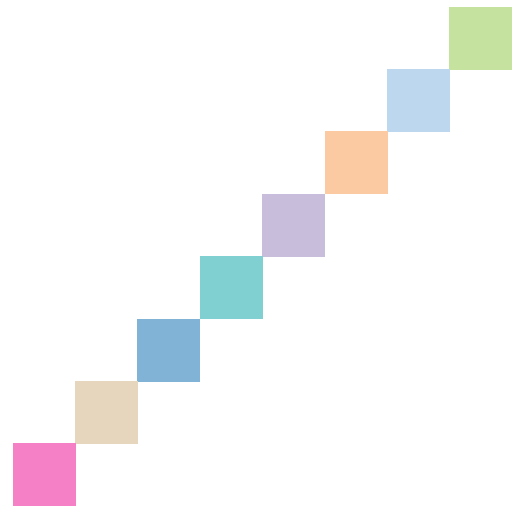
## Dementia post-diagnostic support guidance

Essential information for health  
and social care professionals



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INFORMATION AND  
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in dementia care*



## Foreword

In the five years since my diagnosis at 53, with younger-onset Alzheimers type of dementia I have come by information by accident rather than design. When your diagnosis puts your entire future in question, information gives you power.

I believe the care, support and information received post-diagnosis can hugely influence the trajectory of this disease, not only for the person living with dementia but for their family.

It's critical that any person or family who receives a diagnosis of dementia should, at the very least, receive basic information, support and access to a dementia advisor. Sadly this is not the case for many people living in Ireland today. This guidance document goes a long way to laying the foundation for appropriate information and psycho-social support for those people.

I have been involved in many aspects of dementia advocacy, and unfortunately have seen a lot of good work produced sit on shelves and not put into practice. It is exciting and gives me hope to see that this is a live document that will be used to support people living with dementia.

I am delighted to see that it is a practical and down to earth document and critically that the involvement of people living with dementia is reflected throughout.

Every journey begins with one step, please be the person to take that first step and don't let this guide gather dust!

**Kathy Ryan** • Vice Chair, Irish Dementia Working Group  
(Supported by The Alzheimer Society of Ireland)

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As a former carer, I am delighted to recommend this document as an important guide for those establishing and facilitating dementia post-diagnostic psycho-education programmes for people with dementia and their carers.

The document covers many practical aspects of psychoeducation programmes in order to make them as beneficial as possible for people living with dementia, and their families and carers.

Guidance is provided on considerations to be taken into account when running these programmes, including the importance of pre-attendance screening to understand individuals' particular needs, or awareness of the emotional impact of receiving a dementia diagnosis.

There is also comprehensive information on suggested programme content, for example including interventions such as memory enhancements and strategies, or the need to include advice on financial and legal planning. It is important that the content will provide the necessary signposts for people with dementia to receive information and advice on local supports and services, and therefore be more supported on their dementia journey.

I believe the *The Next Steps: Dementia post-diagnostic support guidance* will be of great assistance to those setting up education sessions that will benefit people living with dementia, their families and carers.

**Judy Williams** • Chair, Dementia Carers Campaign Network

## Funding

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## Acknowledgements

This guidance document was prepared with the assistance of a multi-disciplinary expert Advisory Group (membership listed below), with additional guidance and expert input from members of the Southern Dementia Carers Campaign Network and the Irish Dementia Working Group; engagement with these groups was facilitated by Avril Easton and Clodagh Whelan of The Alzheimer Society of Ireland. We are also grateful to Kathy Ryan and Judy Williams for their contributions.

Thank you to all those who gave their time, knowledge and experience in the development of this guidance document.

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- › Tracey Waldron, Senior Dietitian, St James's Hospital

## Note about terminology

Throughout this document we use the phrase 'care partner' to describe someone who is supporting the person living with dementia. The supporter does not necessarily have to be a family member but they will need to know the person well and play an active role in their life.

Dyadic interventions are interventions where a person with dementia and their care partner attend joint group interventions.

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SECTION

# 1

## Introduction to the guidance document

## 1.0 Introduction to the guidance document

Dementia Services Information and Development Centre (DSIDC) was commissioned by the National Dementia Office (NDO), Health Service Executive (HSE) to develop and produce a guidance document to support the establishment and ongoing facilitation of dementia post-diagnostic psychoeducational programmes for people with dementia and care partners.

This guidance document forms part of the larger Dementia Post-Diagnostic Support Project and furthers the National Dementia Strategy's action area 'Timely Diagnosis and Early Intervention'. It has been produced to support health care professionals in the establishment, organisation and facilitation of evidence-based post-diagnostic psychoeducational programmes. While not to exclude psychoeducational programmes run in long-term residential care, this guidance pertains to people living in the community.

The early stages of dementia represents a crucial entry point for post-diagnostic support where the person diagnosed and their families can come to terms with the diagnosis and start planning for future care together (Whitlatch *et al.*, 2006). As memory is one of the first impairments to manifest in dementia, it is important people with dementia and their care partners are provided with advice and strategies to cope with the impairment and to optimise well-being (Burnham, 2009). The healthcare system can also be complex and navigating through it to find services and supports that are useful can be challenging. Information provision and signposting the person to appropriate services is a key element of this type of early intervention. Each person's personal circumstances mean that tailoring post-diagnostic intervention programmes to meet the individual needs of the person with dementia and the care partner is essential (Mountain and Craig, 2012).

### 1.1 Overview of the guidance document

Insights from people living with dementia and family partners along with a review of the literature and guidance from an expert advisory group have shaped the contents of this guidance document.

The guidance document outlines the available evidence and good practice in relation to dementia psychoeducational programmes for early intervention. It outlines practical considerations on how to run these programmes and provides suggestions for session content.

The guidance document is divided into eight sections as follows:

- 1 Introduction to the guidance document
- 2 Summary of relevant literature
- 3 Practical considerations for programme facilitators
- 4 Programmes content
- 5 Considerations for young-onset dementia and intellectual disability and dementia
- 6 Conclusion
- 7 References
- 8 Appendix and resources. This section contains further information on suggested topics that health care professionals can use in their dementia post-diagnostic psychoeducational programmes

## 1.2 Why focus on early intervention?

The Irish Dementia Post-Diagnostic Steering Group defined post-diagnostic support as 'enabling and assisting people with dementia and their families to live a life of their choosing throughout the continuum of dementia'. Post-diagnostic supports include interventions, therapeutic treatments and activities that build on strengths and abilities that help to maintain and enhance quality of life. Timely diagnosis, early intervention and post-diagnostic support are important elements of the dementia care trajectory and the benefits for people living with dementia, their care partner and families can be substantial. The social contextual model implies the importance of including both the care partner and the person with dementia in post-diagnostic interventions to minimise the potential risk of a decline in well-being and relationship quality as a result of poor communication or misunderstandings (Moon and Betts Adams, 2012). The changes that occur as dementia progresses may influence individual factors and factors shared between the care partner and the person with dementia such as their relationship, how they interact with each other and their level of interdependence (Moons and Betts Adams, 2012).

Both the WHO and Alzheimer Disease International outline the importance of post-diagnostic support in enabling people with dementia and their care partners to come to terms with the disease, plan for the future and make the best use of their current circumstance (O'Shea *et al.*, 2018) and there is growing evidence that post-diagnostic support provided over an extended period is essential for people living with dementia, their families and care partners (The Improvement Hub, 2017). In 2011, Alzheimer Scotland published 'The Five Pillars'; this model of post-diagnostic support contains five key elements or 'pillars' that are essential in supporting people after their diagnosis. The pillars highlight important areas of post-diagnostic support including 'understanding the illness, planning for future care, peer connections, supporting community connections and planning for future decision making' (Alzheimer Scotland, 2011). As part of the Scottish dementia strategy, every person diagnosed with dementia is entitled to one year of post diagnostic support.

The Irish Dementia Working Group, who were consulted as part of the National Dementia Post-Diagnostic Support Project, identified the following areas as important to support them after they received a diagnosis including:

- › Peer support
- › Cognitive rehabilitation therapies
- › Social contact
- › Sharing information
- › Being useful/feeling like they have a purpose

While unhelpful supports identified included:

- › Inappropriate referrals
- › Suggestions that one should attend a day centre or social club

While there is no single model of post-diagnostic support, the end result of post-diagnostic support should be to help people with dementia and their care partners to live as well as they possibly can with the condition (Watts *et al.*, 2013).

### 1.3 What do we mean by psychoeducation?

The World Health Organisation (WHO) recommends that psychoeducational interventions should be offered to families and other care partners of people living with dementia when a diagnosis is made (WHO, 2012). It should also extend to people living with the condition. Psychoeducation is an intervention with systematic, structured and knowledge transfer for an illness and its treatment; it includes emotional and motivational aspects that enable people to cope with their illness and improve treatment efficacy (Ekhtiari *et al.*, 2017). Psychoeducational support groups aim to educate group members on ways of coping while providing a social support setting for group participants (Mason *et al.*, 2006).

Evidence shows that psychoeducation can be most beneficial when the care partner attends a group separate to the person living with dementia; the support is tailored to the specific needs of the group, it includes a mix of education, support and skill building and is time limited and cost-effective (O'Shea *et al.*, 2018).

Work by Mason and colleagues (2006) in the UK evaluating two dyadic psychoeducational groups where the person with dementia attended with their care-partner, found benefits including reductions in levels of depression and an increased ability to cope. The content for the groups included information on memory and future support sessions on coping strategies, medication and emotional adjustment. Mason's review is in line with work undertaken by Goldsilver and Gruneir (2001), where group participants found the educational component of the intervention beneficial and the majority of the group felt their ability to cope was better than before the intervention. Further evidence from the literature is presented below in section 2.0.

SECTION

# 2

## Summary of relevant literature

## 2.0 Summary of relevant literature

An extensive review of nonpharmacological interventions (Olazarán *et al.*, 2010) found evidence of the benefits of interventions including cognitive training, cognitive stimulation, behavioural interventions, activities of daily living and care partner training and support (McDermott *et al.*, 2017).

However, due to the nature of multicomponent post-diagnostic intervention programmes, in that they contain several categories, it is very difficult to know what programme elements work to improve outcome domains and for who they worked (Olazarán *et al.*, 2010) and we must interpret results cautiously because of the differences in the programmes and studies.

A review by Dickinson and colleagues (2017) found that multi-component interventions can help maintain the psychological health of care partners and delay institutionalisation of people living with dementia, but to be the most effective, interventions should have both an educational and therapeutic component in a support group format to further enhance its effectiveness. It is worth noting, that if care partners already know a lot about dementia, information based programmes may not be the most effective form of intervention (Van't Leven *et al.*, 2013). It would be important to therefore screen both the person with dementia and their care partner and tailor the programme to meet need and expectation. Further information on screening is presented in Section 3.0.

Despite most dementia psychosocial research focusing on care partners, recent interventions have included outcomes for the person with dementia (Cooper *et al.*, 2012; Olazarán *et al.*, 2010). Interventions now actively encourage both the involvement of the person with dementia along with their care partner (Moon and Betts Adams, 2012; Van't Leven *et al.*, 2013).

Support groups have been the most widely available intervention available to people living with dementia and their care partners (Goldsliver & Gruneir, 2001; Zarit *et al.*, 2004). These groups help to increase people's knowledge about the condition, to cope with grief, to provide a social environment to reduce feelings of loneliness and isolation and to learn about what resources are available to them (Whitlatch *et al.*, 2006). Other studies have focused on rehabilitation and how this might delay the progress of dementia and help the person to build and implement everyday memory strategies (Clare *et al.*, 2004).

Early intervention provides an opportunity for the person with dementia to participate in future planning and to be involved in care decisions and discussions (Moon and Betts Adams, 2012; Pinquart and Sörensen, 2006). In the early stages of dementia, the person with dementia is still able to maintain a level of independence (Kuhn, 2007) and studies have suggested that in the early stages, people with dementia can talk about their own experiences and can express their needs and opinions on the caregiving process (Moon and Betts Adams, 2012).

The benefits of group therapy, as opposed to individual therapy help people to realise they are not alone. It provides opportunities to spend time with others and can help them to accept their personal situation and to offer mutual support without the feelings of fear and embarrassment (Burnham, 2009). These findings are also in line with feedback from participants from a dyadic Memory Club group where group members could communicate more effectively with each other as a team about current problems and their concerns for the future (Zarit *et al.*, 2004).

For a psychoeducational support group to be successful, facilitators must establish a supportive relationship with programme participants, and they must be viewed not only as an educator but as a resource person too (Goldsilver and Gruneir, 2001). Although group work is beneficial, interventions that have targeted the dyad in the early stages of dementia (Logsdon *et al.*, 2010; Judge *et al.*, 2010; Zarit *et al.*, 2004) also use separate group sessions for care partners and separate groups for people with dementia to talk about important and sometimes sensitive topics (Whitlatch *et al.*, 2017).

Dyadic interventions (Gaugler *et al.*, 2011) can help people living with dementia and their care partner to develop strategies and support structures to manage the condition post-diagnosis (Whitlatch *et al.*, 2006). Despite the limited research focused on how effective dyadic interventions in early-stage dementia are (Moon & Betts Adams, 2012), there is some evidence of the effectiveness of multi-component interventions in a variety of formats; education, support groups, skill building and cognitive rehabilitation with beneficial outcomes for both members of the dyad (Van't Leven *et al.*, 2013; Moon and Betts Adams, 2012; Thompson *et al.*, 2007; Gallagher Thompson and Coon, 2007; Pinquart and Sörensen, 2006; and Elvish *et al.*, 2013), with previous studies also advocating the involvement of both the person with dementia and the care partner in care planning wherever possible (Lyons *et al.*, 2002).

## 2.1 Examples of dyadic post-diagnostic support group programmes from the literature

In the USA, Logsdon and colleagues (2010) evaluation of group therapy is one of the most comprehensive reviews for this type of intervention (Marshall *et al.*, 2015). This randomised control trial of 96 dyads which attended an 'early-stage memory loss support group' has generated the highest evidence post intervention regarding the efficacy of joint support groups, with significant differences in quality of life, depression and family communication for the person with dementia (Logsdon *et al.*, 2010).

Also in the USA, a joint early-stage support group called the 'Memory Club' (Zarit *et al.*, 2004) was evaluated by participants as being 'acceptable'. The structure of the groups, which provided time for the dyad to be together and time apart, was a key success of the programme. The dyads rated 'being with other supportive people', 'being able to express their feelings' and 'feeling less isolated' as other benefits (Zarit *et al.*, 2004). A similar study also called 'The Memory Club' (Gaugler *et al.*, 2011) and based on Zarit's (2004) group, reported that care partners had greater confidence in dealing with mood issues and memory concerns, however there was only a marginal change in people with dementia's perception of depressive symptoms or feelings of efficacy dealing with everyday tasks (Gaugler *et al.*, 2011).

In the UK, an eight-week psychoeducational 'Memory Matters' group was developed by clinicians and delivered by nurses and memory clinic professionals (Marshall *et al.*, 2015). Evaluations showed that participants increased self-efficacy, felt more relaxed about their cognitive problems and valued the group aspect and meeting people in a similar situation (Marshall *et al.*, 2015).

Rik Cheston's 'Living Well with Dementia' (LivDem) is an educational programme with psychotherapeutic elements that is based on previous work by Cheston, Jones and Gilliard (2003), Cheston and Jones (2009) and the 'Memory Matters' group (Marshall *et al.*, 2015). A pilot evaluation of the programme showed strong but not significant improvements in both self-rated quality of life and self-esteem for people with dementia who took part in the programme compared with the control group (Marshall *et al.*, 2015). The reporting of quality of life improvements is also similar to Logsdon's (2010) evaluation.

The 'Taking Control of Alzheimer's Disease: Techniques for Early-Stage Patients and their Care Partners' programme (Silverio and Roberts, 2009) includes joint dyadic sessions and group breakout sessions for discussions about more sensitive issues such as 'changing roles in relationships' (Roberts and Silverio, 2009). These 'joint' and 'breakout' sessions have been used in other studies (Zarit *et al.*, 2004, Logsdon *et al.*, 2010; Whitlatch *et al.*, 2006). At three-month follow-up, participants were more likely than at baseline to be engaged in dementia related coping and health behaviours, including participation in a support group and legal/financial planning (Roberts and Silverio, 2009).



## 2.2 Dyadic multi-component interventions

Many of the dyadic programmes reviewed are multicomponent involving information and education and also counselling based sessions (Whitlatch *et al.*, 2006; Auclair *et al.*, 2009; Quayhagen *et al.*, 2000; Sørensen *et al.*, 2008; Nobili *et al.*, 2004) and goal based cognitive rehabilitation components (Clare *et al.*, 2013; Coe *et al.*, unpublished, 2016; Judge *et al.*, 2013; Bottino *et al.*, 2005; Zarit *et al.*, 1982). Studies including the Support, Health, Activities, Resources and Education programme for early stage dementia (SHARE) (Whitlatch *et al.*, 2017), the Early Diagnosis Dyadic Intervention (EDDI) (Whitlatch *et al.*, 2006) and The Danish Alzheimer's Intervention Study (DAISY) (Waldemar *et al.*, 2006) report benefits including 'reduced dyadic relationship emotional disruption' and 'programme satisfaction' for care partners (Whitlatch *et al.*, 2017) with people with dementia feeling the intervention 'supported them in coping with the challenges of managing everyday life and social relations' (Sørensen *et al.*, 2008).

Cognitive rehabilitation is a highly individualised therapeutic intervention, with personal and realistic goals identified for each client and developed through tailored interventions to meet these goals (Clare *et al.*, 2013). This type of intervention might prevent further disability for people with early-stage dementia (Clare *et al.*, 2011); however, due to its highly individualistic approach, people will differ in their response to various strategies so it is a good idea to try several different strategies to examine what works best for each client (Kelly and O'Sullivan, 2015). Evidence from cognitive rehabilitation trials shows that it is possible to identify meaningful goals and to use rehabilitation methods to bring about behaviour change in areas which are important for people living with early-stage dementia (Clare *et al.*, 2013; Clare *et al.*, 2003). Clare and colleagues (2010) in a single-blind randomised control trial, showed that people living with early stage dementia were able to use compensatory strategies to reduce cognitive demands after implementing cognitive rehabilitation approaches (Coe *et al.*, unpublished, 2016).

Dyadic interventions are diverse in their content, outcomes, measures used, frequency and the person who facilitates the intervention. Outcomes for dyadic interventions vary, some are aimed at maintaining functional abilities for the person with dementia while others are concerned with supporting the care partner to handle the behavioural symptoms, cope with the dementia process and their changing role as a care partner (Graff *et al.*, 2006 and 2007, Gitlin *et al.*, 2010, Logsdon *et al.*, 2010 and Ostwald *et al.*, 1999). A combination of quantitative and qualitative findings from Moons and Betts Adams (2012) review showed that both members of the dyad benefitted from these interventions, particularly in terms of improved cognitive function for people living with dementia and improved socialisation for the care partner. It may be that the 'preventive structure of these less expensive programmes over limited time makes them suitable for broad application for dyads that recognise these problems' (Van't Leven, *et al.*, 2013). From the evidence available, it is likely that health care professionals are using interventions based on their own professional knowledge, service resources and experiences of what works and what doesn't (Laver *et al.*, 2017). It is worth noting

that programmes reviewed for this study vary in duration from four weeks to two years and this time commitment is not always feasible for health care professionals or the dyad (Roberts and Silverio, 2009).

Interventions which have active involvement of both members of the dyad who work together on solutions for future care (Whitlatch *et al.*, 2006, Zarit *et al.*, 2004, Logsdon *et al.*, 2010) have shown positive outcomes in strengthening the dyadic relationship and encouraging long-term planning (Moon and Betts Adams, 2012). One intervention aimed at adapting the home environment to the person with dementia's abilities, improved the person with dementia's rated quality of life (Graff *et al.*, 2007). Two individualised multi-component interventions; built on the assessments of the person with dementia and their care partner, improved care partner quality of life (Olazarán *et al.*, 2010). One of these interventions, which was a high-quality randomised control trial, showed that an improvement in care partners quality of life; attained after the six-month intervention was still evident at 12-month follow-up (Chien *et al.*, 2008). However, Laver's review notes that quality of life is difficult to change through intervention alone (Laver *et al.*, 2017). An Irish study, Coe *et al.*, (unpublished, 2016) in a memory strategy intervention, found that decreased health related quality of life ratings were not dependent on memory function but rather by 'adverse life events' that occurred in the lives of the participants during the study period. Coe's findings suggest caution when measuring the success of a memory strategy intervention by health related quality of life alone (Coe *et al.*, unpublished, 2016).

While more dyadic interventions are emerging, we don't yet know if dyadic interventions are more beneficial than other forms of interventions, there is still a lack of information about outcome goals and not all studies use standardised outcome measures (Van't Leven *et al.*, 2013, Moon and Betts Adams, 2012). Choosing an appropriate intervention depends on a number of factors; the problems that a dyad experience, the stage of mild or moderate dementia, costs, availability and feasibility of the programme (Van't Leven, *et al.*, 2013).

However, if dyadic interventions are found to be beneficial, they may be more cost-effective as compared to implementing separate programmes for care partners and people living with dementia (Judge *et al.*, 2012).

## 2.3 Supportive self-management

Self-management is where the individual with a long-term condition is encouraged to learn to manage their health and identify solutions to meet their specific needs (Mountain and Craig, 2012). Although more commonly used in the management of chronic diseases, self-management of dementia is slowly gaining momentum (Wiersma *et al.*, 2011).

Autonomy, including choice, independence, empowerment and decision making was the most important factor in a 2011 research study conducted in Canada. 88% of respondents, which included people living with dementia, their care partners and health service professionals, felt that self management in dementia was 'feasible', however they noted that 'disease progression' would impact the success of self-management (Wiersma *et al.*, 2011).

Mountain and Craig (2012) identified twelve self-management topics for people living with early stage dementia (Table 1). They used participative research methods to capture views from people living with dementia and their care partners about interventions which they regarded as being helpful in improving quality of life and maintaining independence (Mountain and Craig, 2012).

Despite the lack of evidence in the area and questions of the viability of introducing self-management into dementia care system (Mountain, 2006), Mountain and Craig's (2012) self-management topics could be helpful in developing sessions for post-diagnostic psychoeducational interventions.

For self-management in dementia to be effective, 'early disclosure of the condition is essential' if people are to be provided with the necessary 'emotional support and practical skills for self-management' (Mountain, 2006). Table 1 below outlines the topic areas and dimensions for dementia self-management.

**Table 1: Topics for Dementia Self-Management (Mountain and Craig, 2012)**

Topic	Dimensions
Understanding dementia	Full and timely information about the condition and what to expect
Rethinking dementia	Dementia as part of a process of 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, husbands, wives and partners, rediscovering relationships
Keeping mentally well	Recognising and overcoming depression, managing anger and 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
Building and developing	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	'Planning for the future' was left blank in Mountain and Craig's (2012) table.

## 2.4 Summary of relevant literature

Despite the limited research, dyadic interventions seem to have the potential to benefit care partners by decreasing depression and anxiety, increasing knowledge and coping skills and improvements in cognitive functioning for the person with dementia (Moons and Betts Adams, 2012).

Psychoeducational programmes, when offered to the person living with dementia, their care partners and family are the most effective strategy to prevent or delay progression to a more dependent level (Moon and Betts Adams, 2012), but health care professionals must define their programme goals and target groups well (Smits *et al.*, 2007).

## SECTION

## 3

Practical  
considerations  
for programme  
facilitators

## 3.0 Practical considerations for programme facilitators

The professionals delivering these psychoeducational sessions will no doubt have significant knowledge and skill sets in their chosen fields. However, organising and running these sessions might involve a different set of skills and knowledge base that the facilitators will have to learn.

The following section discusses some of the practical issues that may need to be addressed when establishing a post-diagnostic psychoeducational group.

### 3.1 Screening for post-diagnostic psychoeducational programmes

Screening is used to determine that the person with dementia has adequate awareness of his or her condition to benefit from the group discussions and to identify if either the person with dementia, or the care partner, have any other characteristics that would make it more challenging for them to benefit from a group intervention (Zarit *et al.*, 2004).

How the dyad is screened may be time and resource dependent. Some health care professionals may choose to use a pre-screening interview/questionnaire while others may screen on the first day of the intervention. We would advise that if possible, a pre-screening interview/questionnaire is conducted either in person or over the phone so that a health care professional can determine if the person's level of cognitive impairment is appropriate and if the dyad can attend all intervention sessions.

From the literature the following are suggestions for inclusion and exclusion criteria for the programme

### Inclusions

- 1 All participants, (both people living with dementia and their care partner) should be over 18 years of age and able to give informed consent.
- 2 All participants for post-diagnostic psychoeducation programmes should be referred to the programme and not run as a drop-in programme. Referrals should come from memory clinics, consultant outpatients, old age mental health services, community mental health services, GP practices and referrals from community occupational therapy, speech and language therapy, social work and public health nurses.
- 3 The person with dementia must be in the early stages of dementia, diagnosed in the previous 18 months (Marshall *et al.*, 2015) by a GP, psychiatrist, geriatrician or neurologist.
- 4 The person with dementia should know what type of dementia they were diagnosed with and also have insight into their cognitive disability.
- 5 Ideally, both the person with dementia and their care partner (the dyad) are encouraged to attend each of the programme sessions; however, people with dementia who do not have a care partner should not be excluded on this basis.
- 6 The person with dementia must be able to participate independently in a group setting without their care partner/family member present.

### Exclusions

- 1 People with no formal diagnosis of dementia, a subjective memory complaint (SMC) or mild cognitive impairment (MCI) could be excluded from the programmes; however, inclusion based on these criteria can be left to the professional judgement of the health care professional facilitating the psychoeducation programme.
- 2 People with severe behavioural or psychological symptoms in dementia (BPSD) or with severe illnesses as judged by an experienced, appropriate clinician.
- 3 People with moderate or severe cognitive communication impairment – where there is particular difficulty with auditory comprehension that will impact on their ability to participate and contribute to group discussion and activities.
- 4 To ensure flow of content it is advisable that all group participants are able to speak English. Most people in Ireland speak English and of the 612,018 people who spoke another language at home in Ireland, 508,016 (83%) indicated they could speak English 'well' or 'very well' (CSO, 2017).

## 3.2 Facilitation of psychoeducational programmes

An integral element of success for any psychoeducation programme is how the group is facilitated. As a facilitator, you have to be able to guide the interaction in a group; it is not a one-way track in which you give information to your group it is very much a two-way interaction (MDF, 2008). Teachers, trainers, lecturers and facilitators all have one commonality, and that is to help people to learn; facilitation reflects a change from teacher-centred learning to one that is learner focused (HSE, 2016).

Current practice in Ireland is that most psychoeducational courses are facilitated by one or more health care professionals, including social workers, nurses, psychologists, occupational therapists and speech and language therapists (Guidance Document Advisory Group). It is important that the facilitator of the group has a clinical background, in addition they should:

- Have extensive experience working with people living with dementia
- A good knowledge of the Irish health care system, dementia services and supports
- Familiar with group facilitation

For all psychoeducational programmes, a person-centred ethos is recommended; this respects the person living with dementia, their care partner and their own unique experience of dementia.

More information on facilitating groups can be found in a guide recently published by the HSE (2016). *Facilitating Learning in Groups: A Resource Manual for Facilitators Working in Health and Social Care*.

### Co-facilitation

Co-facilitation, where facilitation is by two people who work together in partnership to help people learn, is used by a number of Irish based dementia specific psychoeducational programmes (Guidance Document Advisory Group). This approach can make life easier for both the group and the facilitators especially when complex issues arise. It is also a recommended approach where (i) one facilitator is less experienced, (ii) for dyadic interventions when the larger group is split into smaller groups, or (iii) when a group is very large (HSE, 2016). In addition, the emotional and psychological impact of receiving a diagnosis of dementia can mean that themes arising during the course of the programme could result in distress that requires immediate individual attention.

Before facilitating a group it's important to determine the approach that will be taken, particularly if the group will be co-facilitated. Box 1 (below) contains some partially completed statements that you might like to consider before beginning either with a potential co-facilitator or on your own. Considering these statements will also provide an opportunity to reflect on how to manage any challenging issues that may arise.



**Box 1: Facilitating Learning in Groups: A Resource Manual for Facilitators Working in Health and Social Care (HSE, 2016).**

My preferred way of starting with a group is...
When someone talks too much, I like to...
When the group is silent, I...
When an individual group member is silent for a long time, I...
If someone comes in late, I like to handle this by...
When co-facilitating, I like to sit (where)...
When co-facilitating, my preferred role when not leading is...
If two group members disagree with each other, I...
If someone in the group gets very upset, I like to...
When I find myself running out of time or when I'm behind schedule, I...
Immediately after a session, I like to...
Three words that would best describe my general style when I'm working with a group are...
The thing that makes me most uncomfortable in groups like this is...
One aspect of my facilitation that I'm not sure about is...
My understanding of confidentiality is...
I would break confidentiality if...

If co-facilitating a group, from the outset, it should be clarified who is the lead facilitator and who is in the supportive facilitator role.

Ideally, co-facilitators should develop, deliver, evaluate and review the psychoeducational programme together. When both are involved in each of these areas, the learning for them and the group participants can be improved as the session content and delivery will be well planned and both can constructively review and evaluate their co-facilitation relationship. If it is decided that changes are required then these decisions can be made as a team (HSE, 2016). Co-facilitators also need to assign tasks or roles; for example, time-keeping, room set-up, printing of any handouts and/or booklets, lead presenter, speaker invitations and ensuring and regulating group participation.

If you are considering co-facilitation, there are a number of elements to consider; firstly, co-facilitation can be twice as labour intensive and twice as costly. Existing programmes in Ireland have responded to this by being creative with programme design and implementation and by using whatever existing resources are available, however, this may not always be possible and you might need to consider other alternatives such as smaller groups or decreased programme frequency.

Effective co-facilitation requires work; co-facilitators therefore need to build their relationship and clarify how they will work and communicate effectively together. If facilitators have not worked together previously, it is a good idea for them to get to know each other in advance of the programme.

External speakers who have expertise in key areas should also be considered (Guidance Document Advisory Group). These speakers can bring a different dynamic to the group and can provide more detailed information about their specialised topic. In addition, The Irish Dementia Working Group suggested inviting a person recently diagnosed with dementia to speak and share their knowledge and their lived experience of dementia with group members is very beneficial and may help people to feel like they are not alone.

Another key consideration for both facilitators is maintaining confidentiality at all times and facilitators should reassure group members at the beginning of each session that all personal information they discuss is confidential.

Facilitators should also ensure that all contact details, records and personal information are securely held and in keeping with GDPR guidelines. You must be fully transparent about how you are using and safeguarding personal data, and to be able to demonstrate accountability for your data processing activities (Data Protection Commission, 2018). If you do not know what your organisations GDPR guidelines are, ask the relevant department who will be able to help you.

### 3.3 How do adults learn?

Andragogy, the concept of adult learning defined by Malcolm Knowles (1984) is based on the assumption that adults want to learn but also recognises that children and adults learn in different ways (Smith, 2002). Adults are very aware of their abilities and experience and, unlike children in school, they also have control over whether they attend training, stay, or walk out (Pfeiffer and Ballew, 1988).

The *Adult Learning Cycle* (Kolb, 1984) highlights the need for both experimental and theoretical learning (HSE, 2016). Adults learn by doing; they want to be involved and to ensure the optimum transfer of learning, they must be actively involved in the learning experience and not just as passive recipients (Pfeiffer and Ballew, 1988).

Training and educational programmes often begin with classroom and lecture based theoretical learning but the *Adult Learning Cycle* is different.

Kolb (1984) lays out four stages of learning:

- 1 'Experiencing' – seeing and doing an activity
- 2 'Processing' – where the learner reflects and analyses the activity
- 3 'Generalising' – this helps the learner to understand what they have experienced and reflected on through a lecture or further reading
- 4 'Applying' – where the learner plans how they will apply what they learned (MDF, 2008)

Kolb (1984) also suggests that learners can learn during all four stages, so people could also; for example, start at stage 3 and work their way through the full cycle (HSE, 2016).

When adult learning is approached in this way, educational programmes can be more 'true to life'; the learner feels that their experience and accumulated expertise is of value to the facilitator and the other members in their group (MDF, 2008).

## 3.4 Planning the programme

Once you have established that there is a need for a dementia specific psychoeducational programme, the next step will be to draw up a global programme and facilitation plan.

The 7Ps framework (Smith *et al.*, 2015) is a very structured way of thinking about how to plan and facilitate an educational programme. This is not the only framework available, but it might be a good starting point.

### 1 Purpose

Why is this programme needed and what are the learning objectives? Are the objectives relevant to the group and has the group had any input into identifying these objectives? Are there similar programmes available elsewhere and will your programme be any different to existing programmes? Is there anything you can learn from other existing programmes?

### 2 Product

It is important to think about how the psychoeducational programme can change the lives of those who attend. After the psychoeducational programme has ended, what will group members bring back to their families, will their outlook on their dementia have changed, and will their care partner feel more confident in their caring role?

### 3 Participants

These psychoeducational programmes are for people living with dementia and their care partners. It is recommended that all participants be screened to determine their suitability to attend the programme. After evaluating the data, possible group members should be selected and programme details discussed with them. If possible, get to know the group participants in advance, as this will also help to determine what content is most suitable for the group, what learning styles they prefer and other details that might be relevant such as their emotional status.

### 4 Process

To ensure that the programme meets the needs and also the expectations of the group members, content will need to be carefully considered. Within this guidance document we have suggested various topics and content that we think would be useful for people with dementia and their care partners. While this is not an exhaustive list, the topics are worth considering and group members should be consulted both verbally and in writing on programme content, either as part of the screening process, post screening, or during the first group session.

Using dementia-inclusive language in the programme content is crucial; avoid using complicated medical terminology, abbreviations, technical language and stigmatising words and phrases such as 'patient', 'sufferer', 'dementing' and 'burden'. Again, group members may be able to offer valuable advice on this.

It is a good idea, once the group members have been selected, to provide a written draft timetable in advance so that the group is aware of upcoming topics, when breaks will take place and when the larger group will be split into a group for people with dementia and a group for care partners (if required). This can also help any participants who are anxious about being part of a group or speaking in front of people they do not know.

Given the cognitive difficulties people living with dementia may experience, how information and learning is imparted requires special attention. Topics should be introduced gradually during each session to reduce information overload for group members.

### 5 Place

When choosing a venue, pick one that has good accessibility, parking and transport links and will accommodate the size of your group. Consider also having smaller rooms for separate group work. The room(s) should be comfortable, have good acoustics, air conditioning and be well lit (HSE, 2016).

Signage for the venue, toilets and fire exits is very important particularly for the initial group sessions when people might get lost. Arrange refreshments, such as tea and coffee if these are required, along with stationery and water.

## 6 Practical tools and equipment

Ensure that all equipment works and ask for the contact details of a relevant IT person in the event that you cannot utilise the computer or connect to the internet. Also have a back up plan in the event that there is no access to IT.

Visual cues can help people to focus and can make the learning process more engaging; these can include a white board, flip chart and handouts. Other visual cues such as post-it notes, short video clips, small notebooks; sheets of paper and verbal reminders can help with concentration and remembering. A 'box' could be provided at the beginning of each session where group members could anonymously place any questions they have. These questions should be dealt with either during the session, or privately, depending on the question(s) asked.

Particular attention should be given to selecting learning strategies that compensate for any cognitive difficulties. For example, a long and complicated presentation may be challenging for members of the group who have difficulty concentrating, so if you are using PowerPoint, keep the slides short and uncluttered, if necessary reinforcing information with pertinent imagery. Avoid using complicated graphs and technical imagery.

Group members should be encouraged to use hearing aids and amplifiers during the sessions and facilitators should also include information in the members resource packs on where these items can be sourced, if required.

Each session should be accompanied with copies of relevant handouts and information booklets, a flipchart, a laptop, charger, connector cables, projector and speakers, registration sheets, evaluation forms and a certificate of attendance, if required.

Use an accessible format for leaflets, handouts and resource material for the group that will facilitate the reading and absorption of new information. Use a clear font such as Arial or Helvetica, no smaller than size 12 and use good colour contrast.

At the end of each session, a brief summary of key take home messages should be given to the group members. These need to be clear, concise and relevant. A final course package containing information summarising details of content, services and supports, should be provided to the group.

## 7 Potential issues

It is important to have a contingency plan in the event that the unexpected happens. For example, if one of the facilitators is unavailable or unwell; the venue for the group becomes unavailable; if no participants show up on the first day or if someone becomes distressed during one of the sessions.

Do a small risk assessment to think about how you might handle some of those unexpected events.

## 3.5 Further considerations

### Advertising the programme

If you intend to advertise your event, give people at least six to eight weeks notice (HSE, 2016), this gives people enough time to arrange getting off work, rearrange hospital appointments family commitments and holiday time.

Advertise your event on notice boards in your local community, hospital, GP surgery and local newspaper. Advertising on social media including Facebook and Twitter is also a good idea. Include just enough information on the poster/information leaflet including time, dates, location, a brief summary of the programme and most importantly a contact name, phone number and email address.

### Size of the group

Variables, such as room size and the number of facilitators available may influence how many group members are in a group. For dyadic groups (person living with dementia and their care partner), there are no recommendations in the literature on group size; facilitators will have to base their group size on the abilities of the participants and resources available. However, the larger the group, the less time facilitators will have to pay attention to individual needs (HSE, 2016).

### What time?

Evening sessions might be convenient for group members who are unavailable during the day due to work and family commitments although others may prefer morning and afternoon sessions. If possible, these questions should be included in the pre-screening interview, but a balance will need to be struck between managing group member requests and the needs of your service.

### Session length, programme frequency and course time frame

There are no recommendations in the literature on the duration and session length of dementia psychoeducational programmes, but most are run once a week over several weeks, varying from four to eight weeks and they usually last from one to two hours. Group needs and abilities and the resources available to the facilitator may influence this, but it is worth investing time getting to know the group and building relationships, as these relationships will be a great support to the group members going forward (HSE, 2016).

## 3.6 Group dynamics

There are other factors that facilitators must consider when developing and facilitating educational programmes for people living with dementia and their care partners.

People come to these groups with different characteristics, memories, emotions and motivations that can affect the person's participation. Some of these characteristics may become apparent during the screening process, however, some may not be obvious and a group facilitator cannot be expected to know how each of the above factors might affect the person's experience in the group.

Most of the motivation for adults to learn is intrinsic and most people who attend dementia specific psychoeducational programmes are there because they would like to learn more about their condition, their own coping mechanisms and plan for their future together with their family. Facilitators should, where possible, encourage self-directed learning, so the group chooses what and how they learn. Once adult learners discover that they have the freedom to act independently within the learning environment as they do in their everyday life, their motivation to learn can be reinforced (MDF, 2008).

### Emotions

Emotion has a huge influence on perception, attention, learning, memory, reasoning, and problem solving, as well as motivating action and behaviour (Tyng, 2017).

The emotional impact of receiving a diagnosis of dementia can be substantial, and while it is not within the facilitator's remit to take on the role of a counsellor, they can make sure that members of the group who do require extra emotional support are given the relevant contact details for counselling services and supports in their local community.

In discussions with the Irish Dementia Working Group for the development of this guidance they suggested it might also be helpful, particularly in the first session, for the facilitator to encourage group discussions about how the group feel about the diagnosis and other emotional and relationship aspects of dementia. It is important that this is only done if the group are ready to do so, it may be later in the programme before they are comfortable discussing these emotions and feelings.

People can also become very anxious within a group environment and might not enjoy doing certain group activities. If there is any doubt about participants and how they are coping within the group, facilitators should privately discuss this with them (HSE, 2016).

### 3.7 Evaluation

Evaluations are an important part of the learning trajectory. Training and facilitation can be quite costly and often places an additional strain on existing resources. To justify why these educational resources are not allocated elsewhere a careful evaluation or follow-up should be conducted.

As facilitators you need to know if the programme achieved its aims and objectives, was it relevant to the participants and was the programme delivered in a professional way (HSE, 2016).

There are two aspects of learning that can be evaluated, the first is the 'content' and the second is the 'process'. When designing an evaluation, it is important to think about what you want to measure/evaluate. Do you want to measure participant's reactions to the programme, did they like or dislike it and how they felt about the programme and you as the facilitator? These are often called 'happy sheets' and they invite group members to assess how they felt about the programme.

Do you want to measure how much the group has learned? This could be a very simple 'true or false' style evaluation or a fun quiz.

Do you want to measure their behaviour? Have they put into practice what they have learned, are they using their memory aids, do the care partners feel that they can now cope better with their partners condition? Measuring behaviour is difficult and group members might find it harder to gauge if their behaviour has changed so soon after the programme has finished and other issues outside of the group environment might make this change more difficult for them. If resources allow, some facilitators may use follow up home visits to measure changes in participant's behaviour post intervention.

Generally speaking, evaluation of all three of the above stages is rare and most evaluations ask about people's reactions to the programme and if it achieved its main objective.

The best advice is to keep the evaluation short and to ask participants 'what worked well and what did not work well' and then follow up later to see if they have implemented what they learned (HSE, 2016).



## SECTION

# 4

# Programmes content

### Links in this section

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## 4.0 Programmes content

### 4.1 Learning about dementia

Evidence from the literature shows that learning and understanding dementia is a key component of all dementia psychoeducation programmes.

In these sessions, information about dementia and its implications are discussed with both the person with dementia and their care partner. There are different ways to approach this session topic and there are many examples from the literature.

As a starting point consider whether the group should be split as people with dementia and their care partners may want to discuss their experience of dementia in different ways.

As outlined in the inclusion criteria it's important that people know what type of dementia they have. There may be questions on how the subtypes differ and what to expect as the condition progresses. Facilitators will need to ensure that all the sub-types of dementia being experienced by attendees of the programme are covered in the discussions.

The different subtypes of dementia that were most commonly described in the research literature were Alzheimer's disease and vascular dementia (Eloniemi-Sulkava *et al.*, 2009; Zarit *et al.*, 2004; Cheston and Marshall, 2019).

In other interventions the subtypes of dementia were not named and instead many looked at how memory works. For example, Judge *et al.* (2012), in their 'Acquiring New Skills While Enhancing Remaining Strengths' (ANSWERS) study, focussed on differences between short and long-term memory processes and used a strengths-based approach to concentrate on 'remaining cognitive strengths'.

People will most likely want to know what to expect and what changes may occur. In the 'Early Diagnosis Dyadic Intervention' (EDDI), Whitlatch *et al.* (2006) helped couples understand more about the changes expected with memory loss and gave practical information about communication techniques, available community resources and the importance of planning for the future.

Zarit (2004) and Cheston and Marshall (2019) both tackle the emotional issues around memory loss in earlier sessions as a part of learning about dementia.

Some people may also like to know what to expect during routine assessments and what to expect in relation to ongoing care; for example, medical interventions and who will manage the person's dementia from a medical perspective.



For suggested content see  
**Appendix 8.1 Learning about dementia workshop (page 57)**



## 4.2 Legal and financial planning

Financial and legal planning was an intrinsic element to all of the programmes identified in the literature and in some cases these sessions involved the issue of driving (Gaugler *et al.*, 2011; Logsdon *et al.*, 2010; Roberts and Silverio, 2009; Cheston and Marshall, 2019).

Other legal aspects covered included mental capacity and future health decision-making. Cheston and Marshall (2019) recognise the difficult nature of raising these issues for discussion, as people will have to face the reality that their dementia will disimprove over time. However, many people will gain satisfaction from taking control over their future lives. The 'LivDem' programme (Cheston and Marshall, 2019) covers 'Making a Will', 'Lasting Power of Attorney' and what they refer to as 'advance statements'. These statements are healthcare proxies that allow people to write down specific future healthcare choices.

Facilitators will need to be cognisant of the sensitive nature of some of the themes raised in this area and they should ensure that all legal and financial advice is accurate and up to date.

Advanced Healthcare Directives, or their equivalent, should form part of the advice given and facilitators should consider asking a guest speaker with expert knowledge in these areas to deliver all or part of this session.



For suggested content see  
**Appendix 8.2 Legal and financial planning workshop** (page 59)



### 4.3 Information and advice on local supports and services

A number of studies (Moniz-Cook *et al.*, 1998; Goldsliver and Gruneir, 2001; Yale, 1999) found that giving information about the disease and referral to or knowledge of local community resources led to better outcomes for people with dementia and their care partners. Other studies (Lodgson *et al.*, 2010; Lingard and Milne 2004) count this provision of information about local resources and support services as a core component of a successful intervention.

The 'Support, Health, Activities, Resources and Education' (SHARE) programme for early stage dementia (Whitlatch *et al.*, 2017), was specifically designed to help people with dementia and their care partners develop their own 'agreed-upon plan of future care' including making decisions about available community supports and resources.

Few studies outlined the type of community resources that should be discussed during these sessions and topics that could be considered for inclusion in this section might be social welfare, voluntary, statutory and private support agencies and non-dementia specific services.

It is important that facilitators are aware of what resources are available locally. The HSE Understand Together website ([www.understandtogether.ie](http://www.understandtogether.ie)) has an online service finder which outlines what services are available by county.



For suggested content see  
**Appendix 8. 3 Information and advice on local supports and services workshop** (page 65)



### 4.4 Memory skills/enhancement/strategies

The negative effects of dementia and memory loss on both the person living with dementia and their care partners is well documented and there is an increasing number of psychoeducational programmes that look to minimise the difficulties caused in people's daily lives by memory problems. While some of these studies involve working with the dyads as an individual unit (Clare *et al.*, 2013; McGrath, 2013; Judge *et al.*, 2012); others have adopted a group approach (Coe *et al.*, 2016; Schmitter-Edgecombe *et al.*, 2008) and the latter are most relevant to your psychoeducation programme.

Many of the multi-component post-diagnostic psychoeducational programmes work on developing memory strategies to promote the independence of the person with dementia as part of the intervention. Cheston and Marshall (2019) tackle this at the beginning of their programme by discussing how memory works and linking this to how memory problems can make a person feel. They distinguish

the differences between short and long-term memory and look at how to make information 'stick'. A number of different strategies are aired including the use of mnemonics and simple memory aids.

Judge *et al.* (2012) developed the 'Acquiring New Skills While Enhancing Remaining Strengths' (ANSWERS) programme that took elements of cognitive rehabilitation (CR) skills and allied them with a broader educational approach. This is a novel intervention as it is designed specifically with the dyad in mind and it is designed for the home setting where the skills learned can be more easily transposed into existing daily routines. Focusing on a 'core set of skills for managing and coping with the symptoms of dementia' (Judge *et al.*, 2012), the dyads were taught a number of CR techniques including prompting, spaced retrieval, accessing the long-term memory as well as the use of basic memory aids such as wall planners, diaries and labelling.

Coe *et al.* (unpublished, 2016) ran a six-week 'Memory Strategy Education Group' (MSEG) for six to ten clients and their care partners. Each session involved an education component and internal and external memory strategies plus an individualised session designed to help the dyad adapt particular strategies to their own circumstances. Strategies included the use of familiar memory aids such as diaries, notebooks and lists to assist with everyday function. Further sessions involved clients identifying their own 'functional memory goals' and strategies were then developed with staff to try and achieve these goals. Research results showed some benefits for those with early dementia in the immediate term but had little impact in the longer term.

Schmitter-Edgecombe *et al.* (2008) used similar techniques with dyads including people with very mild dementia. Their approach, which utilised a notebook that included a 'daily log' for recording and retrieving the details of daily activities, a calendar and a section for note-taking, also engages the care partner as a 'coach'. Their findings add weight to the evidence supporting multi-dyadic interventions that benefit both members of the dyad (Whitlatch *et al.*, 2006; Logsdon *et al.*, 2010).

Giving people a basic understanding of how memory works, may help them to assimilate the information about strategies by making the connection between the experience of memory problems and how these might make a person feel emotionally, this could have many benefits for both parties.



For suggested content see  
**Appendix 8.4 Memory skills/enhancement/strategies workshop**  
(page 69)



## 4.5 Communication

Communication covers a range of issues from discussing emotional issues with care partners and families, to deciding who and how to tell about the diagnosis and the development of specific communication support strategies.

Communication difficulties are inherent in dementia. Cognitive communication impairments are evident across all dementia subtypes and the impact on functional communication abilities will increase with the progression of dementia. Each person with dementia will have an individual communication profile. Early management of communication difficulties can improve quality of life and reduce the negative impact of communication impairment.

Cognitive communication difficulties can be the most frequent and hardest to cope with experiences for care partners (Egan *et al.*, 2010; Braun *et al.*, 2010). Communication partners play an essential role in providing scaffolding for the conversation to enable the person with dementia to communicate to their best ability (Kindell, Keady, Sage, & Wilkinson, 2016).

Interventions focusing on collaborative approaches to dealing with communication breakdown have been shown to be a highly effective way of improving cognitive communication and reducing carer burden. A systematic review on the efficacy of communication training (Eggenberger, Heimerl & Bennett, 2013) suggests that intervention can significantly improve quality of life and well-being of the person and increase positive interactions across a range of settings. This intervention works with the communication dyad (the person living with dementia and their communication partner) to identify positive communication strategies but also to resolve communication difficulties and upskill the partner to resolve communication breakdown efficiently.

Logsdon *et al.* (2010) and Quayhagen *et al.* (2000) researched several programmes for people with dementia and their care partners and found that 'patient-caregiver communication' was amongst a number of domains that improved as a result of the intervention. Nobili *et al.* (2004) discussed verbal and non-verbal behaviour between the care partner and the person living with dementia as part of their structured intervention. Their findings included less agitation and lower care partner stress.

Cheston and Marshall (2019) took a different approach and concentrated on the issue of disclosure, encouraging participants to think about the advantages and disadvantages of telling people about the diagnosis of dementia. Acknowledging the sensitivity of such issues, the researchers also recognise that being open about the diagnosis can bring clarity to communication that wouldn't otherwise be there.

In an Irish intervention, 'Conversation Coaching for People with Dementia and their Communication Partners' (Dooley and Conway, 2016) the issue of improving communication is the core focus. Conversation Coaching provides therapy and training for people with dementia and their communication partners. The programme provides information on how dementia impacts on communication and uses a strengths-based approach to identify what is working well through conversation

analysis. Strategies to improve communication are then developed from this analysis. It was developed from evidence based conversation therapies used with people with aphasia (Lock *et al.* 2001). In an evaluation of the intervention, all participants were found to have improved their functional communication, and the incidence of communication breakdown was significantly reduced (Dooley and Conway, 2016).



For suggested content see  
**Appendix 8.5 Communication workshop (page 72)**



## 4.6 Emotional issues

Tackling the emotional aspects of a dementia diagnosis will require a great deal of tact, experience and understanding from facilitators. It will automatically raise the issue of confidentiality and bring into stark contrast the differing needs of both the person with dementia and their care partners.

Different interventions have dealt with the emotional side of receiving a diagnosis of dementia in different ways.

The 'LivDem' programme placed a particular onus on dealing with the emotional aspects of a dementia diagnosis (Cheston and Marshall, 2019) and, unlike many interventions; these were tackled before any discussion about the disease process itself. Cheston harnesses the supportive nature of the group to foster an environment that allows people to feel safe enough to talk openly about their feelings. He accepts that some will find this easier than others but that the sharing of one's emotional experiences can be 'critical in enabling the group to move forward'. He also notes the 'mixed emotions' that participants may be experiencing about dementia; for example, guilt at struggling with their finances and anger at the loss of independence.

In Zarit's 'Memory Club' (Zarit *et al.*, 2004) and the 'Coping with Forgetfulness' study (Mason *et al.*, 2006) participants are encouraged to examine how memory loss impacts on their sense of self and on their families and close friends. Importantly, as with Cheston, people with dementia and their care partners were grouped separately for this session. This not only recognises the fact that different people require different types of information, it also allows for a safe environment where the individuals can openly discuss their emotions such as anxiety, fear and unhappiness without worrying or angering a partner.

Although not specifically mentioned in the research, loneliness, for both the person with a dementia and the care partner is an important consideration and one that is often overlooked. The way that both groups experience loneliness will differ so facilitators will need to be sensitive to both points of view.



For suggested content see  
**Appendix 8.6 Emotional issues workshop (page 73)**



## 4.7 Physical activity and nutrition

Physical exercise can lead to reduced stress and anxiety; it can improve sleep and appetite and there are a growing number of research studies linking regular exercise with a decreased risk of developing dementia in later life (Livingston *et al.*, 2017). Similarly, there is also a growing body of evidence linking foods that promote a healthy heart with improved brain health. As a result, many of the programmes covered by the research included sessions dedicated to the benefits of physical activity and nutrition. The level of physical activity varied from programme to programme but often involved light exercise such as stretching, walking or Tai Chi (Fritsch *et al.*, 2011).

In developing the Supported Self-management programme, Mountain and Craig (2012) held consultations with people with dementia and their care partners to reach a consensus on the topics that participants might want to include in the programme. Physical and mental wellbeing was seen as integral to supported self-management. Eating and nutrition, sleep, managing fatigue and grading activity, were included within the context of 'keeping physically well'.

Cheston and Marshall (2019) dedicated a session to staying physically active. The importance of physical and mental wellbeing through being physically, mentally and socially active was highlighted as well as promoting a healthy diet.

Nutrition was not discussed in any meaningful way in the psychoeducational research beyond the basic 'brain health' advice; eating five items of fruit and vegetables a day, eat less red meat, eat more oily fish, etc. Issues of weight loss or malnutrition can arise quickly and are an important consideration at all stages of dementia care. Participants can be made aware of possible physiological changes such as loss of appetite, changes to the sense of smell or taste and an increased preference for sweet foods. Eating habits can also change as well as people forgetting to eat. The impact of stress on nutrition can often be overlooked, and this can contribute to weight loss both for the person with dementia and their care partner.



For suggested content see

**Appendix 8.7 Physical activity and nutrition workshop (page 75)**





## 4.8 Environmental interventions

Other interventions have shown to have benefits for people with dementia and their care partners. In particular, Laura Gitlin's work in 'realigning' people's environments in order to delay functional decline has shown improvement in performing instrumental activities of daily living (IADLs), patient engagement and care partner well-being (Gitlin *et al.*, 2010).

In the 'Care of Persons with dementia in their Environments' (COPE) programme (Gitlin *et al.*, 2010) dyads received ten sessions with an occupational therapist (OT) over a four-month period. Routines, roles, habits and concerns were identified and areas of difficulty highlighted. The OT trained the care partner in how to modify the environment and to develop a strategy to ameliorate the area of difficulty. The areas targeted included the use of the telephone, shopping, housework and managing medicines and finances. Self-care activities of daily living were also identified including bathing, dressing, grooming and getting in and out of bed. Gitlin's results showed significant improvements in functional dependence for people with dementia at the four-month follow-up with the care partners reporting a 'great deal' of improvement in their lives at a nine-month follow-up.

Graff *et al.* (2006, 2007) trained people with dementia in the use of aids to compensate for cognitive decline whilst training the care partners in coping behaviours and supervision. Ten sessions of training were given over a five-week period and these were found to have improved the ability of the people with dementia in their daily functions and the care partners had an increased sense of competence. These benefits were still in evidence at the three-month follow-up with all participants in the intervention also reporting improved quality of life.



For suggested content see  
**Appendix 8.8 Environmental interventions workshop  
(including assistive technology)** (page 79)





SECTION

# 5

## Considerations for young-onset dementia and intellectual disability and dementia

## 5.0 Considerations for young-onset dementia and intellectual disability and dementia

Most of the information outlined in this guidance document will be relevant to people with a young-onset dementia and also for people with an intellectual disability who are affected by dementia and their care partners.

However, their distinct needs require separate consideration and some of the suggested approaches will frequently require adaptation to effectively meet these distinct needs. For example, we have to be aware that in some cases the person with a dementia may be living with a person with an intellectual disability, and to some extent, may be reliant on their care. The following section addresses some of these issues.

### 5.1 Young-onset dementia

We know that dementia is not a normal part of the ageing process and in Ireland, there are approximately 4,000 people living with young-onset dementia (Pierce *et al.*, 2014). Young-onset dementia commonly occurs in people aged between 40-65 years old and this earlier onset raises a number of issues for people including changing roles as provider, parent and spouse and the significant adjustment to those changes that is required (Sansoni *et al.*, 2014). Literature agrees that post-diagnostic supports for people living with young-onset dementia need to be age-appropriate, but there is insufficient evidence of 'what works' to inform service design and delivery (Mayrhofer *et al.*, 2017).

The emotional impact of receiving a diagnosis of dementia is considerable and people diagnosed in their 50s, will be just as shocked, saddened, angry and overwhelmed as those diagnosed with later onset, but they may also feel a sense of grief and guilt at the falling apart of their future plans (Alzheimer's Australia, 2007). The needs of people with young-onset dementia are very different to those living with later onset dementia. People are often physically healthy and active with good physical fitness (Sansoni *et al.*, 2014; Mayrhofer *et al.*, 2017) and most do not experience the co-morbidities often associated with old age and later onset dementia (Sansoni *et al.*, 2014). As they are under 65 years of age, they are less likely than older people who may have already retired to be involved in social clubs, or community groups and may not have immediate access to engaging in appropriate activities (Alzheimer's Australia, 2007). If these types of services are available in their local community, it is important that people are informed about these services and pointed in the right direction within their local communities.

People with young-onset dementia have to revise their expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, independence and responsibility for others (Alzheimer's Australia, 2007). Many people living with young-onset dementia can be concerned about an increasing loss of independence especially about driving restrictions or when they will have to stop driving (Sanson *et al.*, 2014). People can have significant financial commitments including mortgage repayments, life assurance, car insurance and their children's education and these commitments can be incredibly challenging when the person living with dementia can no longer work, is forced to retire, or a spouse may give up work or retire in order to become the primary care partner (Mayrhofer *et al.*, 2017).

They may have different family dynamics to the older age cohort, they often have children and teenagers who might be involved in the caring process and in some cases might be the primary care partner. Negotiating how to explain a diagnosis of dementia to children can be extremely challenging and some studies have looked at how children cope with a diagnosis. Themes that have emerged from these studies include concerns about their parent's safety, accepting the diagnosis, developing psychological symptoms including 'depression' and 'stigma' (Allen *et al.*, 2009). Young people also experienced 'carer burden' (Svanberg *et al.*, 2011) and 'high levels of stress' (Gellman and Greer, 2011). After a diagnosis of dementia in the family, children not only face a changing and challenging family dynamic but also have to deal with the usual developmental challenges of growing up and this should not be underestimated or overlooked (Sanson *et al.*, 2014).

Owing to the relatively small numbers of people affected by young-onset dementia it is possible that facilitators will not have sufficient numbers of participants to run a programme solely for those under the age of 65. However, as the experiences of people diagnosed with young-onset dementia and the impact of these conditions differs somewhat from those of people in older age, it is important that facilitators have some specialist knowledge in this area. They will need to have experience and understanding of some of the less common subtypes of dementia and be aware of age-appropriate resources that may be available to support the younger person and their family including 'how to tell children their Mum/Dad has dementia' which was noted as being very important by the Southern Dementia Carers Campaign Network. More details of some of these supports can be found in the Appendix.

### Young-onset dementia – additional information

In addition to the suggested content in Appendix section 8.2 'Legal and financial planning workshop' (page 59), some of the following information may also be of benefit to people under the age of 65.



### **Mortgage protection**

Mortgage protection insurance is compulsory in Ireland. This insurance policy is designed to pay off the balance of your mortgage if you die. Many insurance companies now offer policies that also cover the contraction of a particular specified illness or if you become permanently disabled. It is always worth checking to see if the mortgage protection insurance covers dementia. Some policies are very specific and will state that the policy covers Alzheimer's disease specifically. If the person has been diagnosed with a different sub-type of dementia; for example, Frontotemporal dementia, they should seek the guidance of a medical expert to assist them if arguing their case with an insurance company.

### **Income protection policies for those still in employment**

These policies are becoming particularly popular. They are designed to pay you a percentage of your income if you are unable to work through illness or disability. They are available to those in full-time employment or the self-employed. Income protection policies cover a proportion of your full salary, generally either 66% or 75%. There is normally a deferred period; for example, a period of time that you have to be out of work before any payment is made. This period usually corresponds with the length of time that your employer will pay sick pay. You may need to seek an expert medical opinion to complete the claim process.

### **Critical illness cover**

This is sometimes called Serious Illness cover. It provides a tax-free lump sum if you are diagnosed with a particular illness or disability. You should check the list of conditions that are covered before buying this product as they may differ from company to company.

### **Specified illness cover**

This is similar to Critical or Serious Illness cover. It can be a stand-alone policy or linked to a mortgage protection type policy. They generally cover a range of specified conditions that often include Alzheimer's disease and other dementias.

### **Life insurance/life assurance**

Life insurance/assurance policies generally pay out on the death of the policyholder. However, some policies will pay out a percentage of the cover or the full amount on the diagnosis of a terminal condition. You may need expert medical advice when making this claim.

### **Social Welfare (families)**

If a person is diagnosed with dementia and they have a partner and children they may be able to seek financial support from the Department of Employment Affairs and Social Protection (DEASP). Financial support can include Supplementary Welfare Allowance, Rent Supplement, Mortgage Interest Supplement, Diet and Heating Supplements and Back to School Clothing and Footwear Scheme. DEASP representatives, formerly known as Community Welfare Officers administer these schemes.

## Employment rights

Dementia is a disability and there is much legislation that protects the rights of those people with disabilities. This is particularly true with regards to employment. Individuals who are diagnosed with dementia and are still in employment may need assistance to remain at work. The employer is obliged to take 'appropriate measures' to enable the person with a disability to carry out their work on an equal footing with others. For example, this might mean offering flexible working hours or giving the person certain tasks and substituting others with the employee's consent.

This can be a complex area and the person with dementia may need to seek the advice of their trade union or another professional body, an employee assistance officer or even a solicitor with experience in employment law. People with dementia should be encouraged to remain in employment if this is what they wish to do. If they choose to stop working then they should seek to terminate work in a way that will provide the most positive outcome for them. This may include sick pay, redundancy payments or pension packages. Again expert advice is recommended. (See *Your Employment Equality Rights Explained* an Irish Human Rights and Equality Commission resource, Free Legal Advice Centre and Citizen's Information for more details).

## Goods and services

The Equal Status Acts 2000–2012 (the 'Acts') ban discrimination on a number of grounds including gender, race and disability. The legislation is designed to prevent somebody being treated less favourably because of who they are. This also extends to the main carers of the person with the disability where the person requires care on an ongoing basis. (See *Your Equal Status Rights Explained* an Irish Human Rights and Equality Commission resource for more details).

## Discretionary medical card

Even if your income is above the financial limits set in the means test you may still be able to qualify for a discretionary medical card if you can show that you would experience financial hardship without one. There is no specific application form for this medical card and, as a result, there is no clear pathway to access it. The HSE Medical Card and GP Visit Card National Assessment Guidelines advise that a person first apply for the Medical Card as normal and then, if refused on income grounds, to reapply requesting to be assessed for a discretionary medical card. Medical officers will then assess the case to determine whether paying medical bills etc. will cause financial hardship.

Due to the complicated nature of this application it would be advisable to seek expert help from a skilled healthcare or legal professional to assist with this process.

## Resources

The resources listed under the Resources section 8.2 'Legal and financial planning workshop' (page 59) will also be beneficial for people under the age of 65 too.



## 5.2 Intellectual disability and dementia

If the person who has been diagnosed with dementia also has an intellectual disability, it is essential that the family and any care partner has a good understanding of dementia, how it will progress and accurate information on any supports, assistance, social welfare benefits or tax breaks that may be available. As this is a *dual disability* scenario, one needs to be aware that the supports available may come from alternative sources and not just from organisations such as the Alzheimer Society of Ireland.

The diagnosis of dementia should be shared with the person with an intellectual disability. How that information is given will very much depend on the individual's ability to process and understand what they are being told. It will provide the person with the opportunity to be as involved as possible in decision-making around their care as well as helping them to make sense of the changes that are happening. Watchman *et al.*, (2015) suggest building on the background knowledge that the person may have to help explain the diagnosis. They may already know someone with dementia or have experienced an illness, and this may help them to understand the diagnosis.

Other non-pharmacological approaches for engaging with people with dementia such as life story work, reminiscence, reality orientation and validation therapy can all be successfully adapted to the needs of people with an intellectual disability (Dodd *et al.*, 2005). To ascertain their suitability, interventions should be reviewed on a regular basis.

Reactive or responsive behaviours including 'agitation, aberrant motor behaviour, anxiety, elation, irritability, depression, apathy, disinhibitions, delusions, hallucinations, and sleep or appetite changes' (Dodd *et al.*, 2017), are regular features in people diagnosed with dementia and there is a suggestion that responsive behaviours may be even more common in people with Down syndrome and dementia (Dekker *et al.*, 2015).

It is crucial that care partners and professionals are aware that these symptoms may be caused by something other than dementia and these should be carefully considered when looking for a solution to a situation. Dodd and colleagues (2017), recommend that a 'positive behaviour support approach' be taken when dealing with responsive behaviours. This approach 'emphasises person-centred values, aims to enhance community presence, increases personal skills and competence and ensures dignity and respect is maintained for the person being supported' (Dodd *et al.*, 2017).

The post-diagnostic support needs of a person with an intellectual disability and dementia are, broadly speaking, the same as those of the general population with dementia. However, how those needs are addressed and how information and support are communicated will require an alternative approach in order to maintain quality of life and personal dignity.



## Intellectual disability and dementia – additional information

Post-diagnostic psychosocial interventions with people with an intellectual disability (ID) and their care partners will, in the main, be undertaken by specialists in the area. While much of the information on the various supports, interventions, management of conditions, etc. can be relayed to those caring for people with ID and dementia in a group setting, it is likely that inputs with the person with ID and dementia will be on a one-to-one basis. The type and range of inputs will be dependent on the severity of the intellectual disability.

Immediately post-diagnosis it may be necessary to concentrate on explaining the diagnosis itself in terms that are understandable and resonate with the individual.

In *Jenny's Diary*, which is 'a resource to support conversations about dementia with people who have an intellectual disability', Watchman and her colleagues (2015) suggest using a four-step approach to helping someone with an ID understand their diagnosis. This involves ascertaining how much the person knows about their past, what is happening to them in the present and what they think will happen to them in the future. The next step involves breaking down and simplifying the information that needs to be shared. Watchman suggests using any background knowledge or relevant experiences that the person may have about dementia or other illnesses. Attention will also need to be paid to any current difficulties or worries that the person may be experiencing and a decision made on how much information about the future can be shared.

Communication aids such as *Talking Mats* may prove useful in this process. How the situation is explained to the individual is reassessed regularly as the dementia progresses. The information that is given and how it is imparted will change over time.

*Jenny's Diary* also includes useful sections for care staff, family members and friends, helping to explain possible changes and improve the support of the person with an intellectual disability and dementia.

Other useful resources for working with people with ID and dementia are life story tools such as the Open University app *Our Story*. Originally developed as a literacy aid for small children its adaptability has made it a popular application. Available for use on iPad, *Our Story* works as a life story book. The template allows the creation of bespoke headings that can then have photographs, words, videos and voice recordings added to them.

People with ID may also find themselves living with someone with dementia, quite often an ageing parent, and this can create complex situations. It may be necessary to use approaches similar to *Jenny's Diary* to explain the changes that are happening to their relative and helping them plan for the future. Specialist support and interventions are likely to be necessary in order to maintain these families successfully in the community.

## Employment rights

It is possible that a person with an intellectual disability who is diagnosed with a dementia may still be in employment. They have the same rights and protections under the Employment Equality and the Equal Status Acts as other people with disabilities. As with those with a young onset dementia this can be a complex area and expert advice should be sought in helping to determine the best possible outcomes.

See *Your Employment Equality Rights Explained* an Irish Human Rights and Equality Commission resource, Free Legal Advice Centre and Citizen's Information for more details.

## Goods and services

The Equal Status Acts 2000–2012 (the 'Acts') ban discrimination on a number of grounds including gender, race and disability. The legislation is designed to prevent somebody being treated less favourably because of who they are. This also extends to the main carers of the person with the disability where the person requires care on an ongoing basis. (See *Your Equal Status Rights Explained* an Irish Human Rights and Equality Commission resource for more details.)

## Resources · Intellectual disability and dementia

### Jenny's Diary

<http://www.learningdisabilityanddementia.org/jennys-diary.html>

### Talking Mats

<https://www.talkingmats.com/>

### Open University 'Our Story' app

<http://www.open.ac.uk/creet/main/projects/our-story>

SECTION

6

# Conclusion

## 6.0 Conclusion

The current National Dementia Strategy recognises that, following a diagnosis of dementia, people and families will require a significant amount of emotional and practical support to enable them to cope with the challenges confronting them and that well organised and co-ordinated local services will need to be on hand to assist them.

The Strategy also acknowledges that much can be done to help people with dementia to live as well as possible following a timely diagnosis.

We know from the research (Moniz-Cook *et al*, 1998; Goldsilver and Gruneir, 2001; Yale, 1999) that providing relevant information about the particular dementia and providing knowledge of local community resources can improve the outcomes for people with dementia and their care partners. The question that remains is which is the best vehicle or format to impart this knowledge.

As we can see from the review of the literature in this area, there are many different and varied approaches to answering this question, many of which hold great validity and have been shown to benefit people with dementia and their care partners to a greater or lesser degree. It is not the purpose of this guidance document to dismiss or undervalue these approaches but rather to highlight them and suggest elements that might work well within the Irish context without being prescriptive.

When formulating any educational programme one has to decide for whom the programme is intended. After reviewing the literature and careful consideration, it was decided that this guidance document would support a group dyadic approach that had, at the same time, a flexibility that would allow facilitators to adjust and adapt programmes to best suit the needs of the participants. It was felt that not only was this a cost-effective method of delivery, but that it treated both the person with dementia and the care partner with equal consideration and respect, yet *allowed* space for both parties to express themselves openly without fear of upset or embarrassment. The decision as to who attends the programmes will always be at the discretion of the facilitator(s). Younger care partners under the age of 18 for example could be considered, dependent on the role that the individual has in the person with dementia's life and their awareness of the condition.

In the section on 'Practical Considerations' there are a number of important points that facilitators should reflect on when planning their intervention. The assessment or screening of participants' needs careful thought, as it will determine how the group coalesces and moves forward through the programme. The

grouping of individuals with similar conditions, types of difficulties and levels of understanding will aid both facilitators and participants. Through discussions with professionals who are currently providing a variety of psychoeducational programmes, there was a uniform wish to be as inclusive as possible and that all diagnoses of dementia should be catered for provided that the participants would gain benefit from attendance. It was also felt that there should be flexibility around the timeframe that a person with dementia attends a programme. This flexibility is at the discretion of the facilitator(s) but Marshall *et al*, (2015) suggests that a person attend within 18 months of a diagnosis. The pre-attendance screening was also viewed as important by care partners from the Southern Dementia Carers Campaign Network who felt that it would help if facilitators were aware of people's journey to their diagnosis and to get to know about their symptom experience, the stage of dementia and type of dementia they have.

Co-facilitation was viewed as the preferred option for a successful intervention. Having two facilitators on hand allows the group to be split into two in order to allow both care partners and people with dementia the emotional space to openly discuss issues. It can also potentially provide wells of additional and mutually supportive skill sets for the group to draw from. Similarly, the use of guest speakers with in-depth knowledge in specific areas could also be beneficial for all.

Programme duration and frequency differed greatly throughout the research. Many of the interventions lasted between six and eight weeks and appeared to last from one to two hours. Facilitators may have to try altering the length, frequency, duration and the time of day of the intervention to suit a particular audience, with the duration of the intervention likely to have a bearing on the topics covered.

With regard to course content, the literature delivered a diverse array of choices and these often reflected the professional backgrounds of those delivering the programmes. The use of guest speakers may help to keep the intervention broad based.

Cheston's approach in his 'LivDem' intervention is quite novel in the way that the weekly topics are structured. Sessions one through four cover topics such as memory aids and strategies; the impact of anxiety and stress on memory and feelings, emotions and relationships before tackling 'what is dementia?' in week five. The aim is to allow the group to get to know each other and identify participants with similar difficulties before starting to open up about their shared experiences. This approach offers an opportunity to learn how stress and anxiety impact on memory and to identify coping mechanisms that may help alleviate these.

When it comes to learning more about dementia, research on the different programmes show that the majority of them only covered Alzheimer's disease and vascular dementia. Feedback from the Southern Dementia Carers Campaign Network show that those caring for people with different sub-types of dementia could feel neglected by this. It is therefore important that other dementia sub-types are discussed or that there is an avenue that allows the person with dementia and their care partner to talk with a professional about their specific condition.

Other topics that might be considered for inclusion would be helping participants to understand both the assessment process and follow-on care from their local health services and the potential impact of other co-morbidities.

The fragmented and complex nature of health and social services can be extremely confusing for those with limited experience and may put them off seeking additional support. Many people with dementia will have other health problems to contend with, such as arthritis, depression, diabetes etc. and the need to optimally manage these co-morbidities should be highlighted.

Not all the topics covered in a programme will suit every participant and there is a strong argument to provide people with a choice about what they would like to learn. This could be done at the beginning of the intervention or during the screening process, providing those attending with a *menu* of topics for the group to choose from and prioritise. This could provide some logistical problems for facilitators but does offer a degree of empowerment to both the person with dementia and their care partner.

The aim of greater empowerment for people with dementia is central to the concept of self-management programmes. The aim of supportive self-management is to improve quality of life by giving people with dementia and their care partners the information, knowledge and skills to manage their daily lives. Supportive self-management not only empowers the person with dementia, but it also forces the health professional to keep the person as their primary focus in any interventions. It changes their role from passive recipients of care to active partners (Bahrer-Kohler and Krebs-Roubicek, 2009). As we move towards a rights-based approach to dementia care it is likely that supportive self-management type interventions will become the norm for people with early diagnoses.

The literature has shown that time limited, multi-component, psycho-educational sessions for groups can be a cost-effective use of time and resources if properly targeted and delivered. These interventions should not happen in isolation and should be regarded as the start of people's engagement with local support structures.

Post-diagnostic psychoeducational supports should be one of the first steps in instilling an element of hope into those newly diagnosed with dementia and their care partners. Lawlor (unpublished, 2018) argues that the general public are all too aware of the 'tragedy narrative' that surrounds dementia and that this negativity has a 'corrosive effect' on public attitudes towards dementia and those affected by it. By providing people with accurate information about dementia and about living with the condition, including relevant details of available supports and resources, then perhaps a more realistic and hopeful appraisal of the situation can be attained.

SECTION

7

# References

## 7.0 References

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## SECTION

# 8

# Appendix and resources

### Links in this section

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## 8.0 Appendix and resources

### Suggested content for programme

Note: The following information is not a prescriptive list of what should be contained in a post-diagnostic psychoeducational programme. Indeed practitioners will want to include information that pertains to their local community. Also the suggested programme content does not necessarily have to be delivered in the order it appears in this guidance document.





Suggested content for  
4.1 Learning about dementia (page 26)

## 8.1 Learning about dementia workshop

A detailed knowledge and understanding of the differing causes of dementia, their symptoms and available treatments is vital if a facilitator is going to deliver an effective psychoeducational programme. Poor knowledge and understanding could lead to detrimental information or advice being given to the person with dementia and their care partner.

Information that will be needed (but not necessarily used) by the programme facilitators:

- Knowledge of the main dementia sub-types: Alzheimer's disease, vascular dementia, mixed-vascular/Alzheimer's disease, Dementia with Lewy Bodies, Frontotemporal dementia. Knowledge of other, less common conditions such as Primary Progressive Aphasia (generally a rare form of Alzheimer's disease), Parkinson's disease dementia and Posterior Cortical Atrophy would be beneficial.
- The causes of dementia.
- Dementia facts and figures (current and projected).
- Frequently occurring symptoms or behaviours associated with different types of dementia. For example, apathy, restlessness, forgetfulness, word-finding difficulties, misplacing items, walking.
- Aetiology of such behaviours – damage to brain v's psychosocial and/or environmental reasons.
- Knowledge of local services and supports.

Knowledge and understanding of common medications and treatments used for dementia:

- Facilitators will need to be familiar with the drugs prescribed for Alzheimer's disease (donepezil, galantamine, rivastigmine and memantine), their possible side-effects and efficacy. This information is available in the Public Information Leaflets (PIL) either online or in the packaging of the medication. The most common side-effects for the acetylcholinesterase inhibitors (donepezil, galantamine and rivastigmine) are stomach upset/nausea and disturbed sleep. The stomach upset/nausea will, for most people, settle down after a few days. If side-effects persist, the medication may have to be withdrawn. Rivastigmine is available in a 'patch' format rather than a tablet and some people may prefer this.
- Facilitators will need to be aware of the medications that can be used to modify the risk factors for dementia; for example, aspirin for blood pressure, statins to control cholesterol, medications to manage diabetes.
- Knowledge of other treatments used for issues such as responsive behaviours would be advantageous. These behaviours might include increased agitation, anxiety, aggression, constant walking etc. and many of the treatments would include coping strategies. These coping strategies could include Cognitive Stimulation Therapy, Cognitive Rehabilitation, lifestyle work and reminiscence work.





Doctors may also prescribe low doses of anti-psychotic medications to deal with aggression or if the person is in acute distress. Anti-psychotic medication should only be prescribed for a short period of time and only as a last resort as they can be harmful to the person with dementia.

## Resources

**Dementia Services Information and Development Centre. (2015).**

**Coping with the Early Stages of Dementia.**

[http://dementia.ie/images/uploads/site-images/Early\\_Dementia.pdf](http://dementia.ie/images/uploads/site-images/Early_Dementia.pdf)

**Dementia Services Information and Development Centre. (2016).**

**Cognitive Impairment and Dementia: A Practical Home Guide to Daily Living for Family Members. DSIDC. Dublin.**

<http://dementia.ie/images/uploads/site-images/CognitiveImpairmentandDementia.pdf>

**Dementia Services Information and Development Centre. 'What is Dementia?'**

<http://dementia.ie/information/overview/information-overview>

**HSE Dementia Understand Together**

<http://www.understandtogether.ie/about-dementia/>

**HSE Dementia Understand Together**

<http://www.understandtogether.ie/get-support/living-well-with-dementia/>

**The Alzheimer Society of Ireland 'About Dementia.'**

<https://www.alzheimer.ie/about-dementia.aspx>

**The Alzheimer Society of Ireland. (2014).**

**I have dementia...first steps after a diagnosis.**

[https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/I-have-dementia-First-Steps-Diagnosis\\_websitefinal\\_pdf.pdf](https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/I-have-dementia-First-Steps-Diagnosis_websitefinal_pdf.pdf)

**The Alzheimer Society of Ireland. 'I am a carer.'**

<https://www.alzheimer.ie/Living-with-dementia/I-am-a-carer.aspx>

**The Alzheimer Society of Ireland. Dementia Carers Campaign Network.**

<https://www.alzheimer.ie/Get-Involved/Campaigning/Advocacy/Dementia-Carers-Campaign-Network.aspx>

**The Alzheimer Society of Ireland. (2014).**

**Living with Dementia – an introduction for family members.**

[https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Living-with-Dementia\\_web-2014.pdf](https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Living-with-Dementia_web-2014.pdf)



## 8.2 Legal and financial planning workshop

### Legal advice

Making a Will and planning for the future is incredibly important. It allows a person to decide how their assets; including money, possessions and any property will be distributed when they die. If a person does not make a will, their estate will be divided in a way that is set out in law (Law Society of Ireland, n.d.).

The legal situation with regards to decision-making ‘capacity’ and people with dementia is currently evolving in Ireland. There are a number of organisations that produce clear and accessible information on these topics and these are listed in the resource section of this guidance. However, facilitators should possess a good working knowledge of the issue of capacity and how it may be affected by dementia. Facilitators should also be aware of the approximate cost of legal processes before making suggestions or recommendations to participants as this information is generally not available in the literature. For example, the cost of drawing up an Enduring Power of Attorney can vary significantly from solicitor to solicitor and individuals or couples should be advised to ‘shop around’ to secure the best deal. There is also a cost to register the Enduring Power of Attorney in the High Court if an individual loses capacity to make decisions and families will need to be aware of this before proceeding.

The issue of Advanced Healthcare Directives is also covered by the recently enacted assisted decision-making legislation and is thus in a similarly evolving situation. An Advanced Healthcare Directive allows one to state the kind and extent of medical treatment, including surgery, that one might require in the future. This presupposes that a person would not be in a position to make those decisions at the point of time when they would be required. The ‘Think Ahead’ document published by the Irish Hospice Foundation contains a useful form that one can complete to record wishes and preferences.

### Medical fitness to drive

Decisions around driving or the cessation of driving can be problematic and extremely contentious for both medical professionals and people with dementia and their families. The development of the *Medical Fitness to Drive Guidelines* (Road Safety Authority and the National Office for Traffic Medicine) has brought a greater degree of clarity about our rights and responsibilities as the state of our health changes. Links to the above guidelines and other driving-related resources are available in the resource section of this guidance.

In Ireland, a diagnosis of dementia does not automatically preclude one from driving. People can often continue to drive with no issues following a diagnosis of dementia. Many individuals will make the decision themselves when to stop driving or will gradually withdraw from driving, passing that task on to other family members.

In order to continue to drive legally and with full protection a person will have to carry out three main tasks.





The first of these involves insurance. Vehicle insurance is designed to protect the insured person financially from any physical damage or bodily injury that might occur in a traffic accident. It also protects one from any financial liability that might arise from an accident. Every vehicle insurance policy has a clause that requires the insured person to notify the vehicle insurance company if there is a change in their health status. Therefore, a diagnosis of dementia needs to be reported to the insurance company. Failure to do so may invalidate the insurance policy and leave the individual fully liable for any damage caused in an accident regardless of blame.

Each vehicle insurance company in Ireland has their own protocol for dealing with a client who informs them of a diagnosis of dementia and the insured person will need to be guided by this information.

Secondly, the insured person is required to inform the National Driving Licence Service (NDLS) of their diagnosis. This requires the completion of driving licence application form (this acts as a 'change of circumstance' form) and the completion of the Driving Licence Medical Report form (this will be completed by the person's GP). The applicant is required to present the forms in person at a NDLS centre along with their current licence, their PPS number and proof of address. In certain circumstances, proof of residency may be needed.

Thirdly, it is becoming increasingly commonplace for doctors to request that the person with dementia undertakes an 'on-road' driving assessment. The person with dementia can expect an assessment that will last approximately 45-minutes and will assess 'a range of driving situations such as high and low-speed zones, controlled and uncontrolled intersections, parking and manoeuvring'. Furthermore, 'the drive will include situations that you would normally face when driving in your local area but if relevant to you may also include motorway or dual carriageway driving' (RCPI, RSA, 2015).

The GP or referring doctor may be able to provide you with the details of suitably qualified driving assessors in your area. These are private arrangements and the cost of the assessment will be covered by the individual. The National Office for Traffic Medicine produced a list of on-road assessment services that are available around the country. It is important to bear in mind that many of these providers will have different levels of experience and expertise and one should, therefore, be certain that the assessor chosen has the necessary knowledge and skills in the area of dementia.

## Financial matters

The facilitator of this workshop should have a good basic grasp of Social Welfare entitlements including:

- Eligibility for Social Welfare payments; for example, Disability Allowance, Illness Benefit, Invalidity Pension, Carers Allowance, Carers Benefit, Carer Support Grant, Home Carer Tax Credit. (See the latest information regarding benefits on Citizen's Information <http://citizensinformation.ie/en/> and The Department of Employment Affairs and Social Protection <http://www.welfare.ie/en/Pages/home.aspx>



- › Eligibility for GP Visit Card, Medical Card or Long Term Illness Scheme, Discretionary Medical Card (See latest information regarding medical cards on Citizen's Information <http://citizensinformation.ie/en/> and the HSE <https://www.hse.ie/eng/>)

## General advice in relation to financial matters

The ability to deal with money and manage finances is often one of the first 'life skills' to be impacted in dementia. There is some good advice available from organisations such as the Alzheimer Society of Ireland and the HSE Dementia Understand Together, however, these will not always provide answers for difficult problems. Often you will need to explore potential solutions directly with the person with dementia and/or their primary care partners.

## Misplacing money

This is a perennial problem that is raised by care partners in clinics, surgeries, support groups and social clubs throughout the country. Often the level of concern it raises will be dependent on the amount of money that goes missing.

The best solutions are the ones that are arrived at with the agreement of the person with dementia and we should try to ensure that people have access to their money wherever possible. Most individuals like to have 'walking around' money on their person and it may be possible to arrive at an agreement whereby the individual is given a daily or weekly allowance. If the allowance is given in cash then it might be advisable to give this money in lower denomination notes rather than larger denomination notes. This can give the appearance of having more money, but also on a practical level, it is easier to misplace one or two notes as opposed to ten.

The new range of mini Bluetooth trackers that can be placed in purses and wallets and work in conjunction with smartphones may offer a technological solution, if one is required.

If there is an issue with a person withdrawing too much cash from the ATM or bank then a face-to-face conversation with your local bank branch manager may help. For instance, a cap on daily, weekly or monthly withdrawals might be put in place, again with the consent of the person with dementia wherever possible. However, if a couple have a joint bank account both parties are supposed to have the capacity to manage that account and all its activities. When one party is unable to manage the account, the bank would have the power to suspend all activities until there was a resolution to the situation. This is rarely used and most banks are happy to work with people and their families to find workable solutions.

The Banking and Payments Federation Ireland published the useful 'Guide to Safeguarding your Money Now and in the Future' and this could be used as a handout.



## Bill payments

Although it is now common to pay bills and other payments by Direct Debit or Standing Order it can sometimes be useful to arrange to make these payments at the Post Office, if this can be carried out safely. The process of taking a bill and cash to make a payment can help maintain and reinforce feelings of control and independence.

It is also a good idea to put utility company bills into joint names as many companies, due to data protection issues, will now only talk to the person whose name is on the bill. This can cause difficulties if the person with dementia is trying to rectify a complex issue.

## Online banking

Online banking can also be a useful tool for people living with dementia. This gives us the ability to view our bank accounts and review statements at any time we wish. This might be useful if a person is particularly anxious about their financial resources. This also allows remote monitoring of a bank account to ensure that there is no suspicious activity occurring. If a person is able to operate an ATM but there are concerns over budgeting or erratic spending then a subsidiary account could be set up for the person with dementia. This subsidiary account could then be topped up electronically as needed by the family. Again this can help maintain feelings of control and independence.

Any suspected financial abuse should be reported to the local HSE Safeguarding Vulnerable Adults team.

## Resources

**Dementia Services Information and Development Centre. (2017).**

**Pills, Bills and Wills. DSIDC. Dublin.**

<http://dementia.ie/images/uploads/site-images/PillsBillsWills.pdf>

**Alzheimer Society of Ireland and The Irish Hospice Foundation. (2013).**

**I have dementia... How do I plan for the future?**

[https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/ASI-Plan-For-the-Future-2016\\_-web.pdf](https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/ASI-Plan-For-the-Future-2016_-web.pdf)

**Free Legal Advice Centres. (2014). Enduring Power of Attorney.**

<https://www.flac.ie/publications/legal-info-leaflet-enduring-power-of-attorney/>

**The Irish Hospice Foundation. Think Ahead.**

<https://hospicefoundation.ie/programmes/public-awareness/think-ahead/>

## Medical fitness to drive

**Road Safety Authority and the National Office for Traffic Medicine (2016).**

**Medical Fitness to Drive Guidelines. Dublin.**

[http://www.rsa.ie/Documents/Licensed%20Drivers/Medical\\_Issues/SI%C3%A1inte agus Tiom%C3%A1int Medical Fitness to Drive Guidelines.pdf](http://www.rsa.ie/Documents/Licensed%20Drivers/Medical_Issues/SI%C3%A1inte agus Tiom%C3%A1int Medical Fitness to Drive Guidelines.pdf)



**National Programme Office for Traffic Medicine. (2016). On-Road Driving Assessment (ORDA) Information. Dublin.**

[https://www.rcpi.ie/wp-content/uploads/2016/02/1\\_Onroad-Driving-Assessment-Information.pdf](https://www.rcpi.ie/wp-content/uploads/2016/02/1_Onroad-Driving-Assessment-Information.pdf)

**Alzheimer Society of Ireland. (2014). Driving and Dementia.**

[https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/Driving-and-dementia\\_FactSheet\\_web.pdf](https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/Driving-and-dementia_FactSheet_web.pdf)

### Financial matters

**Citizens Information**

[http://citizensinformation.ie/en/social\\_welfare/](http://citizensinformation.ie/en/social_welfare/)

**Department of Employment Affairs and Social Protection**

<http://www.welfare.ie/en/Pages/home.aspx>

**HSE Medical Cards and Schemes**

<https://www.hse.ie/eng/cards-schemes/>

**Banking and Payments Federation Ireland 'Guide to Safeguarding your Money Now and in the Future'**

<https://www.bpfi.ie/wp-content/uploads/2018/06/BPFI-Guide-to-Safeguarding-Your-Money-Now-and-in-the-Future.pdf>

### Employment rights

**Irish Human Rights and Equality Commission. (2015). *Your Employment Equality Rights Explained, Guide to the Employment Equality Acts 1998–2011.***

[https://www.ihrec.ie/download/pdf/ihrec\\_employment\\_equality\\_rights\\_explained.pdf](https://www.ihrec.ie/download/pdf/ihrec_employment_equality_rights_explained.pdf)

**Citizens Rights Employment Rights**

[http://www.citizensinformation.ie/en/employment/employment\\_rights\\_and\\_conditions/](http://www.citizensinformation.ie/en/employment/employment_rights_and_conditions/)

**Free Legal Advice Centres**

<https://www.flac.ie/>

**The Alzheimer Society of Ireland. (2012). *I have dementia...I have rights. Know your rights.***

[http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/ASI-I-have-dementia-I-have-Rights\\_web.pdf](http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/ASI-I-have-dementia-I-have-Rights_web.pdf)

**Sage Advocacy**

<https://www.sageadvocacy.ie/>





**Sage Advocacy information on the Assisted Decision Making (Capacity) Act 2015**  
<https://www.sageadvocacy.ie/resources/legal-rights/decision-making-capacity>

### **General advice in relation to financial matters**

**HSE Dementia Understand Together**

<http://www.understandtogether.ie/get-support/living-well-with-dementia/legal-and-financial/>

**The Alzheimer Society of Ireland**

<https://www.alzheimer.ie/Living-with-dementia/I-am-a-Carer/Plan-for-the-future.aspx>

**HSE Safeguarding Vulnerable Adults Team**

<https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/>

*Note: Legal and financial information can go out of date. One should always ensure that the information being provided is accurate and up to date.*

### **Information for children and young adults**

**Dementia Services Information and Development Centre (2018).**

*The Brain – from the Fantastic to the Forgetful.* A dementia awareness programme for Junior Cycle and Transition Year Interactive PDF. DSIDC. Dublin.

[http://dementia.ie/images/uploads/site-images/The\\_Brain\\_Textbook\\_Workbook.pdf](http://dementia.ie/images/uploads/site-images/The_Brain_Textbook_Workbook.pdf)

**Dementia Services Information and Development Centre. (2017).**

*The Brain – from the Fantastic to the Forgetful*

<http://dementia.ie/images/uploads/site-images/DementiaAware.pdf>

**The Crystal Project. (2018). *Feathers in My Brain*.** The Crystal Project. Cork.

<https://www.crystalproject.ie/crystal-project-childrens-book-feathers-in-my-brain>

**Alzheimers Research UK – Dementia Explained for Kids**

<https://kids.alzheimersresearchuk.org/>

**Young Dementia UK – Telling Children**

<http://www.youngdementiauk.org/telling-children>

**Dementia Australia – Dementia in my Family**

<https://dementiainmyfamily.org.au/>





## 8.3 Information and advice on local supports and services workshop

The cornerstone of community support is the local GP. The GP may be able to provide general advice and information but they are also often the gatekeepers to the more specialist hospital teams including Geriatricians, Psychiatry of later life, Neurology, and allied health professions such as Occupational Therapy, Physiotherapy and Social Work.

The Public Health Nurse (PHN) is based in the local health centre and is generally a valuable repository of local knowledge and is a gatekeeper to local services. They are able to offer advice and information as well as practical assistance with medications, dressings, etc. They can also refer people to other services such as the Home Support Service (formerly known as 'home help or homecare packages'), meals-on-wheels, day care and respite care depending on what is available in the local community. Where there is an established Primary Care Team some of these non-medical tasks might also be carried out by another healthcare professional such as a social worker.

However, it should be noted that in some areas of the country the PHN/Community nursing service might not assess clients who do not hold medical cards. The reason for this is linked to the legislation relating to community nursing services, which specifies that HSE may provide nursing service to clients with 'full eligibility' – but there is no requirement in legislation to provide community-nursing services to non-medical cardholders. In many/most areas community based nursing services will assess for Home Support Services and deliver nursing services/support to non-medical card holders subject to the level of available resources in the area.

As a result of this, it is strongly recommended that people diagnosed with a dementia apply for a medical card and, if unsuccessful, attempt to apply for a discretionary medical card.

The HSE Home Support Service provides support to help people in the community who have an illness or a disability. The provision is not means-tested and there is no charge to the recipient of these services. The Home Support Service mainly provides personal care and help with domestic tasks, it does not provide nursing or medical care.

The Home Support Service can include in its allocated hours a range of additional supports including extra home help hours, nursing care, day care, respite care, physiotherapy, occupational therapy, etc. to support the needs of the client.

Although the Home Support Service for older people is designed for those over the age of 65, the HSE does allow the scheme to be accessed by those under the age of 65. 'If a younger person's assessed needs; for example, early onset dementia, can be best met by services designed for older people then occasionally such an application may be considered' (HSE website, May 2018).





In the last few years, the Department of Health has begun to provide a limited number of 'Intensive Home Care Packages' (IHCP) including Dementia Intensive Home Care Packages. These provide more supports and services than covered by the standard Home Support Service and are earmarked for people who require a significant level of assistance. The focus of the IHCP is to provide personalised flexible packages of care.

To get access to the Home Support Service one's needs will be assessed by a HSE health professional, in most cases this will be the Public Health Nurse.

### **Dementia specific community services**

The main provider of dementia specific community services in the country is the Alzheimer Society of Ireland. They run a range of community services including a national telephone helpline, carer support groups, day care, respite care, home care and social clubs. They also have a number of Dementia Advisors in various locations around the country. Dementia Advisors can provide valuable information about local services and supports and help people stay connected to their local community.

Support for care partners and families is available through Family Carers Ireland. They run support groups, offer counselling and advocacy, rights and entitlements and legal advice. In some instances, they may provide home care services. The Dementia Carers Campaign Network is an advocacy group, facilitated by the Alzheimer Society of Ireland, that campaigns for the distinct needs of the carers of people with dementia.

A relative newcomer to dementia community supports is the Alzheimer Café network. The Alzheimer Café model originated in the Netherlands and its success there has been replicated in Ireland where the number of cafés has continued to grow since their inception in 2011. The cafés generally run for a couple of hours once a month. They are a mixture of socialising over a cup of tea or coffee and a piece of cake and a short talk about some aspect of dementia followed by a discussion and questions.

The most comprehensive directory of local services related to dementia can be found on the Understand Together website <http://www.understandtogether.ie/get-support/service-finder/>

### **Non-dementia specific services**

Other non-dementia specific services that operate on a national basis and might be able to provide services and support are The Irish Men's Sheds Association and the Irish Wheelchair Association. Before referring to these services it would be prudent to check that they are able to assist.

Local councils may be able to offer services to assist a person with dementia to retain levels of independence and remain in their local communities. The Housing Departments of all local councils have a budget to provide grants for housing adaptations for people with disabilities.



## The housing adaptation grant for people with a disability

'A housing adaptation grant is available where changes need to be made to a home to make it suitable for a person with a physical, sensory or intellectual disability or mental health difficulty to live in.' (Citizens Information website, 19/12/18) This could involve, for example, a bathroom adaptation, providing ramps for wheelchair access or the fitting of a stair-lift.

## Mobility Aids Grant Scheme

'The Mobility Aids Grant Scheme provides grants for works designed to address mobility problems in the home.' (Citizens Information website, 19/12/18). Some local councils use it to fast track grant aid to cover a basic selection of works to address mobility problems. It is available to people with a disability as well as those over the age of 65.

## Housing aid for older people

This grant is used to improve the condition of a person's home and can allow repairs and improvements to be carried out. The scheme is mainly for those over the age of 66 but may assist those under the age of 66 if they are experiencing genuine hardship.

## Telecare

People over the age of 65 with dementia and their carers can avail of telecare services. Telecare services traditionally comprised of pendant and wristband alarms but these now include an extensive selection of monitors and detectors including motion sensors, fall detectors, flood monitors, smoke and heat detectors, exit sensors and pill dispensers amongst others. Telecare in Ireland is managed by the governmental agency Pobal but is administered by a number of community groups at the local level. If interested, one should visit the Pobal website for the full list of community providers or contact Age Action for further details of the local community groups and grant funding. There is often a fee involved with telecare services.

## Resources

### The Alzheimer Café

<http://www.alzheimercafe.ie/>

### AZURE – for people living with dementia and their family, friends and carers

<https://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/Azure-project.aspx>

*(Contact individual galleries and museums to check programmes and availability)*

### The Forget-Me-Nots-Choir

<http://forgetmenots.ie/>



### Family Carers Ireland

<https://familycarers.ie/>

### The Irish Men's Sheds Association

<http://menssheds.ie/>

### Irish Wheelchair Association

<https://www.iwa.ie/>

### Dementia Specific Services in the Community: Mapping Public and Voluntary Services

<http://www.understandtogether.ie/news-and-events/news/Final-Report-Dementia-Specific-Services-Mapping-Project.pdf>

### Dementia services and support in Ireland finder

<http://www.understandtogether.ie/get-support/service-finder/>

### Dementia Friendly Communities

<https://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities.aspx>

### Dementia Friendly Communities Toolkit

<https://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Communities.aspx>

## Mobility Aids Grant Scheme housing aid for older people

### Citizens Information

[http://www.citizensinformation.ie/en/housing/housing\\_grants\\_and\\_schemes/mobility\\_aids\\_grant\\_scheme.html](http://www.citizensinformation.ie/en/housing/housing_grants_and_schemes/mobility_aids_grant_scheme.html)

## Housing aid for older people

### Citizens Information

[http://www.citizensinformation.ie/en/housing/housing\\_grants\\_and\\_schemes/housing\\_aid\\_for\\_older\\_persons\\_scheme.html](http://www.citizensinformation.ie/en/housing/housing_grants_and_schemes/housing_aid_for_older_persons_scheme.html)

## Telecare

### Age Action

[https://www.ageaction.ie/sites/default/files/attachments/260816\\_information\\_note\\_on\\_personal\\_alarm\\_providers.pdf](https://www.ageaction.ie/sites/default/files/attachments/260816_information_note_on_personal_alarm_providers.pdf)

### Senior Alert Scheme

<https://www.pobal.ie/programmes/seniors-alert-scheme-sas/>

### HSE Dementia Understand Together – Memory Assistive Technologies

<http://www.understandtogether.ie/training-resources/helpful-resources/memory-assistive-technologies/>

### Memory Technology Resource Rooms in Ireland

<http://alzheimer.ie/services-support/technology-and-you.aspx>



## 8.4 Memory skills/enhancement/strategies workshop

This session should concentrate on the simple, straightforward advice that can be given to people with impaired memory. For more advanced interventions, people may wish to seek out Cognitive Stimulation Therapy (CST) or Cognitive Rehabilitation (CR) if available.

Facilitators will have to have a good working knowledge about memory and other cognitive domains such as concentration and attention and be able to articulate this knowledge in a way that is accessible to the group.

### Information about the brain and memory

The 'Jog your Memory' Occupational Therapy Group and 'The Memory Matters' Group both based in Dublin, provide simple information on memory and attention in a relatable and easy format. Similarly, facilitators could include a 'Meet your brain' type session with simple, accessible and relatable information on the brain and how it works, different brain areas/lobes and structures that contribute to the different types of memory and the differences between short and long-term memory. Emphasise the importance of attention and how strategies such as doing one task at a time, limiting demands, concentrating on new information and staying positive can all help to focus and improve attention.

Easy to understand information about the brain and memory can be found in the Resources section of this guidance document.

### External strategies

External memory aids are one of the most important approaches in memory rehabilitation (McGrath, 2013). The Memory Rehabilitation Programme (MRP) (McGrath, 2013), uses external compensation strategies such as alarm clocks, calendars and memory boards to help clients with memory retrieval.

The dyad may already use many of these strategies, and group discussions could include the pros and cons of many of these memory aids. Facilitators should stress the importance of routine and establishing daily habits, being organised, writing lists, de-cluttering their home and should encourage the use of external compensation memory aids including dry wipeboards, post-its, diaries/calendars, shopping lists, mobile-phone reminders, keeping a list of important contact numbers, apps and a memory notebook.

### Recall strategies

Recall or internal strategies include repetition, mnemonics, chunking and method of loci.

Repetition is a simple recall strategy that can be used every day, repeating information helps to form memory traces so the information is there when we need to recall it. Facilitators can demonstrate repetition in the weekly sessions by





repeating the group members names, this really simple technique emphasises how simple and easy it is to repeat names in casual conversation to help with memory recall (Jog Your Memory, Facilitators booklet).

Mnemonics are learning techniques that help people retain information for longer. Techniques include using mental pictures to remember numbers and names. So for the person who has difficulty remembering their banking details this could be a simple technique of imagining a shape that their PIN number makes on the ATM number pad (Alzheimer's Society UK, 2009).

Chunking information together into smaller groups or categories can help when a person needs to remember large amounts of information, such as their shopping list (Kelly and O'Sullivan, 2015). A good example of chunking would be grouping the items on their shopping list together into food categories; for example, fruit and vegetables (apples, oranges and carrots), dairy (milk and cheese) and meat (beef and pork) (Kelly and O'Sullivan, 2015).

Method of loci involves memorising information and placing each item that the person wants to remember around a familiar location the 'loci'. Visualise a room that you know very well, go through the room and pick out specific locations; for example, the sofa, a coffee table and visually place the items you would like to remember in these locations. When trying to recall the items, remember the room and the specific locations where you placed the items.

More specific interventions, which are especially useful if specific goals have been identified by the dyad, include face-name recall, number recall, fluency training and list/object recall (Kelly and O'Sullivan, 2015). These cognitive rehabilitation strategies target specific goals and should be carried out by a healthcare professional skilled in CR techniques and interventions.



## Resources

Dementia Services Information and Development Centre. (2017).

*The Brain – from the Fantastic to the Forgetful.*

<http://dementia.ie/images/uploads/site-images/DementiaAware.pdf>

Your Amazing Brain

[www.youtube.com/watch?v=fP7u6wwbsZo](http://www.youtube.com/watch?v=fP7u6wwbsZo)

Hello Brain Website

<http://helloworldbrain.eu/en/>

Sea Hero Quest

<http://www.seaheroquest.com/site/en/>

Alzheimer Society UK. (2009).

*Memory Handbook: A practical guide to living with memory problems.*

[https://www.alzheimers.org.uk/sites/default/files/pdf/the\\_memory\\_handbook.pdf](https://www.alzheimers.org.uk/sites/default/files/pdf/the_memory_handbook.pdf)

## Cognitive rehabilitation

Kelly, M., & O'Sullivan, M. (2015). *Strategies and techniques for Cognitive Rehabilitation: Manual for healthcare professionals working with individuals with cognitive impairment.* The Alzheimer Society of Ireland. Dublin.

## Cognitive stimulation therapy

Spector, A, Thorgrimsen, L., Woods, B, & Orrell, M. (2006). *Making a difference:*

*An evidence-based group programme to offer CST to people with dementia.*

Hawker Publications Ltd. London.

Aguirre, E, Spector, A., Hoe, J., Woods, B., & Orrell, M. (2012). *Making a Difference 2:*

*Volume Two: An Evidence-based Group Programme to Offer Maintenance Cognitive*

*Stimulation Therapy (CST) to People with Dementia.* Hawker Publications Ltd. London.



## 8.5 Communication workshop

This workshop could cover a number of different areas including the interpersonal relationships between people with dementia and their care partners, whom to tell about a diagnosis, how to impart that information and communication issues that may arise from the dementia; for example, word-finding difficulties or forgetting people's names.

The discussion on more complex areas of cognitive communication difficulties may need to be tackled by a Speech and Language Therapist. This might cover topics such as:

- › An exploration of what communication is.
- › Verbal and non-verbal communication.
- › How dementia might affect communication; for example, difficulty staying on a topic, problems following a conversation, word-finding difficulties and the interpretation of social situations.
- › Communication strengths; for example; reading, recognition of people, signs or places reminiscence.
- › Memory support; for example, life story book, reminiscence behaviour as communication.
- › Communicating effectively with a person with dementia; for example face-to-face in a quiet environment, clear, jargon-free language, use of prompts, gestures, writing, allowing extra time, use of closed questions.

Discussing a diagnosis is a very sensitive area and will require careful consideration. The information and advice given will be dependent on who is the recipient of that information; for example, the information given to an employer will be very different from breaking the news of a dementia diagnosis to young children.

See resource section 8.2 'Legal and financial planning workshop' for more information on explaining dementia to children and young adults.

### Resources

**The Alzheimer Society of Ireland – Dementia inclusive language**

<https://www.alzheimer.ie/About-Us/News-and-Media/Media-Guidelines-to-Dementia-Language.aspx>

### Speech and language therapy services

**Irish Association of Speech and Language Therapists**

<http://www.iaslt.ie/>

**Independent Speech-Language Therapists of Ireland**

<https://isti.ie/>





## 8.6 Emotional issues workshop

Facilitators will have to exercise caution and be fully aware of their own limitations when dealing with interpersonal relationships. The emotional needs of the group could be very high, the Southern Dementia Carers Campaign Network advises that facilitators should be aware of the different needs of people living with dementia and their care partners and be sensitive to both. As previously mentioned and this has been reinforced by the Irish Dementia Working Group, it might be helpful for the facilitator to encourage group discussions about how the group feel about the diagnosis and other emotional and relationship aspects of dementia during the first session, but it is important that this is only done if the group are ready to do so.

If the issues are complex, then a referral requesting access to professional counselling or therapy for concerned members of the group would be advisable. The public options that are available include:

- 1 Local Mental Health services which are accessible via GP referral.
- 2 Counselling in Primary Care is free for medical card holders for up to eight sessions with an accredited therapist/counsellor.
- 3 National Counselling Service for clients who have experienced abuse in childhood.
- 4 Private services are also available. Getting advice from the GP would be useful here or contact the Psychological Society of Ireland.

### Stigma

Stigma reveals itself in many ways and can have a significant affect on a person with dementia's quality of life leading to further isolation and loneliness and a reluctance to seek help (ADI, 2012). A better understanding and awareness of dementia can reduce levels of stigma that is prevalent in most countries and at various levels (ADI, 2012).

Facilitators should be prepared to engage in discussions with group members on their experience of stigma from members of the public, the media, their family and friends.

Group members might also like to discuss ways of informing members of their wider community, such as their local bank or supermarket that they are living with dementia. The Alzheimer Society have a very useful card '*I have dementia*' which can help people living with dementia to navigate their way through every day services and business. See the resources section which follows for details.





## Resources

### Counselling services

**National Counselling Service for clients who have experienced abuse in childhood**

<https://www.hse.ie/eng/services/list/4/mental-health-services/national-counselling-service/nationalcounsellingservicebranches.pdf>

**Psychological Society of Ireland**

<https://www.psychologicalsociety.ie/>

**Counselling in Primary Care**

<https://www.hse.ie/eng/services/list/4/mental-health-services/counsellingpc/>

### Relationships

**HSE Dementia Understand Together – Carers, families and friends**

<http://www.understandtogether.ie/get-support/living-well-with-dementia/carers-families-and-friends/>

**The Alzheimer Society of Ireland 'I have dementia' help card**

[http://alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/ASI-HelpCard\\_website\\_final.pdf](http://alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/pwd%20resources/ASI-HelpCard_website_final.pdf)



Suggested content for  
4.7 Physical activity and nutrition (page 32)

## 8.7 Physical activity and nutrition workshop (includes information on social engagement and stress management)

### Physical activity

Two-thirds of the Irish population aged 50 years and older report low or moderate levels of physical activity, while only one-third report high levels of activity (TILDA, 2016). Middle-aged and older Irish adults with high levels of physical activity report 'greater participation in social activities, better self-rated health, better quality of life and lower loneliness scores compared to those with low physical activity levels' (TILDA, 2016). Physical activity reduces the risk of cardiovascular disease, cancer and falls, and older adults who exercise have better cognition function than their non-exercising peers (WHO, 2010).

The [National Guidelines on Physical Activity for Ireland](#) recommend 30-minutes a day of moderate activity for five days a week or 150 minutes a week (HSE, 2009). People aged 65 years and older should add muscle strengthening and balance exercises two days per week to reduce the risk of falls (HSE, 2009).

Physical activity can include leisure time activities, brisk walking (the most common activity for older adults), cycling and swimming, occupational activities including household chores and gardening and planned exercise or taking part in sports as part of daily, family or community activities (TILDA, 2016).

### Social engagement

Social interactions with friends, relatives, societies, volunteer groups or community groups are hugely beneficial for maintaining good brain health and you don't have to be a social butterfly to reap the rewards. Meet friends and family for a catch up over a cup of coffee, join a book club, your local sports group or choir or a community group that interests you. Social interaction stimulates your brain cells to grow new connections and strengthens those already formed (Hello Brain, 2014) and most importantly, being social and meeting people is a fun and enjoyable activity!

### Keeping mentally active and stimulated

Neuroplasticity, also called brain plasticity, refers to the brain's ability to change throughout life. The human brain has an extraordinary ability to reshape itself by forming and strengthening new connections between neurons. Every time we learn a new skill; for example, learning a new sport or learning a new fact, our brain changes contributing to greater cognitive reserve.

Cognitive reserve seems to be built from a lifetime exposure to cognitive stimulation. It provides an explanation for why people with more years of education might have a lower risk of dementia. However, cognitive reserve is a theoretical construct; it is something that researchers believe to exist because it explains a number of associations, but they cannot directly measure or observe it. But they





think it includes changes to the structure and function of the brain to make it more resilient and more flexible.

To increase cognitive reserve, you need to challenge your brain with new learning, learning new skills such as learning a new language or musical instrument and keeping socially connected.

## Stress management

Our body and brain are equipped to help us to respond to stress, it helps us stay alert and motivated. When we experience a stressful situation, such as encountering an angry dog or speaking in public, a 'fight-or-flight' response is activated. This response refers to a physiological reaction that occurs when we feel physically or psychologically terrified. These physiological reactions can include a dry mouth, tense muscles, dilated pupils, increased heart rate and breathing. Our body usually returns to normal levels within an hour after the threat has disappeared, but if we activate the stress response too much, our body is in constant 'fight or flight' mode and this stressful state can wreak havoc on our immune system, our cardiovascular health and our cognitive health. It's important to note that the threat doesn't always have to be real, sometimes these threats can be imagined and can often follow from over thinking situations or thinking the worst will happen.

Talk to the group and find out if they are already practising relaxation techniques like mindfulness and yoga. Discussion and education on different coping strategies will be beneficial for people living with dementia and their care partners when faced with strong and prolonged stressors.

Strategies to help with stress can include exercise, mindfulness and relaxation techniques, such as deep breathing. Other techniques include grounding techniques like rooting awareness in the body; for example, feeling the soles of your feet while walking or focusing on breathing in and out are examples of how to achieve this. These techniques when practised regularly can assist the dyad to be more present in the moment, stop the mind from wandering and reduce anxiety.

It might be beneficial to include five-minutes of simple relaxation techniques such as deep breathing and mindfulness in each of your programme sessions.

## General lifestyle considerations

### Physical activity and exercise

Advice as above.

### Diet

A healthy diet, low in saturated fats, sugar and salt and high in leafy greens, bright coloured fruits and vegetables, pulses, lean meat and fish are all good brain health foods.



### Smoking

Advice should be given to the group on quitting and where to avail of smoking cessation programmes in their local health area.

### Alcohol

Alcohol should be taken in moderation and avoided late at night to ensure a restful beneficial sleep.

### Sleep and sleep hygiene

Getting seven to eight hours of sleep every night is recommended and routine is important, try to go to bed at the same time every night.

The bedroom should be a sleep zone; good sleep hygiene involves avoiding computer screens and mobile phone screens as the blue light from these screens suppresses the secretion of sleep inducing melatonin.

Eat light meals early in the evening rather than feasting late into the night and avoid stimulants such as alcohol, coffee, tea or other caffeinated drinks.

### Resources

**Dementia Services Information and Development Centre. Brain Health and Dementia Risk Reduction.**

<http://www.dementia.ie/information/brain-health-and-dementia-risk-reduction>

**HSE Dementia Understand Together**

<http://www.understandtogether.ie/about-dementia/what-is-dementia/brain-health/>

**The Alzheimer Society of Ireland**

<http://www.alzheimer.ie/brain-health.aspx>

**Hello Brain Website**

<http://helloworldbrain.eu/en/>

### Physical activity

**Siel Bleu Ireland**

<http://www.sielbleu.ie/>

**Go for Life Programme**

<http://www.ageandopportunity.ie/what-we-do/physical-activity-sport>



## Diet

### SafeFood

<http://www.safeFood.eu/Healthy-Eating/Food,-Diet-and-Health.aspx>

Irish Nutrition and Dietetic Institute. (2017). *Nutrition and Dementia: A practical guide when caring for a person with dementia.*

Irish Nutrition and Dietetic Institute. Dublin.

The Alzheimer Society of Ireland. (2017). *Eating Well with Dementia: practical tips for family carers.*

[https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/ASI-Eating-well-with-Dementia\\_-website\\_2017.pdf](https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/ASI-Eating-well-with-Dementia_-website_2017.pdf)

## Social interaction

### University of the Third Age (U3A)

<https://www.ageaction.ie/how-we-can-help/lifelong-learning-u3a/what-university-third-age-u3a>

### Community Groups

<http://ageandopportunity.ie/who-we-work-with/community-groups>

### The Forget-Me-Nots choir

<http://forgetmenots.ie/>

### Social Clubs

<https://www.alzheimer.ie/Services-Support/About-our-Services/Social-Clubs.aspx>

## Quit smoking

### HSE QUIT

<https://www.quit.ie>



Suggested content for  
4.8 Environmental interventions (page 33)

## 8.8 Environmental interventions workshop (including Assistive Technology)

### Environmental interventions

There are a number of simple adaptations that can be made to the everyday environment that can promote independence and support people with dementia with everyday functions. The kind of adaptations that need to be made will depend on the individual participants and any particular difficulties that they may have.

This is not an exhaustive list, and facilitators should encourage participants to develop their own solutions to particular problems. The first priority for any environment is general safety, so basic precautions should be taken. For example, removing loose rugs or mats (trip hazard), moving trailing electric cables (trip and possible fire hazard), the fitting of smoke, fire and carbon monoxide alarms and the use of fire retardant materials where possible.

Other topics that may be discussed:

- **Adequate lighting** – helps us to perform daily activities and move around safely and the ‘quality and quantity of light can affect our well-being and mental health’ (DSIDC, 2017).
- **Noise** – excessive noise can be debilitating and should be controlled.
- **Temporal orientation** – helping people remain orientated for time can help reduce stress and anxiety for both the person with dementia and their care partner. Examine different ways of helping people keep track of the time, day and date.
- **Using the kitchen** – ensuring safety in the kitchen is paramount. Smoke alarms must be fitted and functioning. The checking of perishable foodstuffs may be necessary. Grouping together of items/equipment might be useful. For example, bread, butter, jam and the toaster all in the same place. Declutter and only have necessary items/equipment on show. Consider removing cupboard doors to maximise visual access.
- **Bathrooms** – grab rails may be necessary for support, colour contrasting may need to be introduced; for example, a coloured toilet seat and the boiler water temperature adjusted to prevent scalding.
- **Spatial orientation** – sometimes as a cognitive impairment progresses people can become disorientated. Ensuring that people carry identification that shows their name and address and a contact number would be advisable. It may become necessary to advise neighbours, local shopkeepers, Gardaí, etc. that the person has dementia. Many mobile phones now come equipped with a GPS tracker and this may be useful if someone loses their way.





- **Medications** – many people with dementia continue to manage their own medications with low levels of monitoring and/or support. If the person is taking a lot of medication, it may be advisable to have the medications reviewed by a doctor to see if any can be safely stopped or if they can be taken at a time of the day that is a better fit for the person's routine. Most pharmacies will now blister pack medications for their customers. Pill organisers and dosette boxes can also help. Alerts on a timer or mobile phone can act as reminders to take medications.

These are only a very few suggestions and many people will have developed their own strategies to compensate for difficulties they encounter. People can seek advice, and in some cases, equipment from their local Occupational Therapists. They can be contacted via the local health centre.

### Assistive technology

Assistive technology (AT) refers to any device or system that helps to maintain or improve the function of a person with a disability.

People often think that AT involves complicated, technical or expensive equipment to remedy a difficulty. This is often not the case. For example, a diary could be regarded as a piece of AT as it helps us to remember what is happening on a particular day.

AT is a huge area, and facilitators will have to address each situation as it arises. The two questions that should always be asked when considering AT as a solution are:

- 1 What is the simplest piece of AT that will resolve the problem?
- 2 Can it be purchased on the high street as opposed to a specialist supplier?

Memory Technology Resource Rooms are now available in most Community Healthcare Organisation (CHO) areas around Ireland. People with memory impairments can access these rooms and try out different devices and strategies to help maintain functional independence.

More information on the location of the Memory Technology Rooms can be found on <http://www.understandtogether.ie/training-resources/helpful-resources/memory-assistive-technologies/>





## Resources

Dementia Services Information and Development Centre. (2016).  
Cognitive Impairment and Dementia: A Practical Home Guide to Daily Living  
for Family Members. DSIDC. Dublin.

[http://dementia.ie/images/uploads/site-images/  
CognitiveImpairmentandDementia.pdf](http://dementia.ie/images/uploads/site-images/CognitiveImpairmentandDementia.pdf)

Centre for Excellence in Universal Design (2015).  
*Dementia Friendly Dwellings for People with Dementia, their Families and Carers.*  
National Disability Authority. Dublin.  
<http://universaldesign.ie/Built-Environment/Housing/Dementia-Friendly-Dwellings/>

The Alzheimer Society of Ireland  
<https://www.alzheimer.ie/Services-Support/Technology-and-you.aspx>

Assist Ireland  
<http://www.assistireland.ie/eng/>

HSE Dementia Understand Together – Memory Assistive Technologies  
[http://www.understandtogether.ie/training-resources/helpful-resources/  
memory-assistive-technologies/](http://www.understandtogether.ie/training-resources/helpful-resources/memory-assistive-technologies/)

Memory Technology Resource Rooms in Ireland  
<http://alzheimer.ie/services-support/technology-and-you.aspx>

DeafHear  
<https://www.deafhear.ie/DeafHear/home.html>

NCBI  
<https://www.ncbi.ie/>

AT Dementia  
<https://www.atdementia.org.uk/>

## Notes

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Building a  
Better Health  
Service

Seirbhís Sláinte  
Níos Fearr  
á Forbairt

National  
**Dementia**  
Office

**dementia**  
understand together

National Dementia Office  
HSE, Block 6, Central Business Park, Clonminch Road  
Tullamore, Co. Offaly

[www.understandtogether.ie](http://www.understandtogether.ie)



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