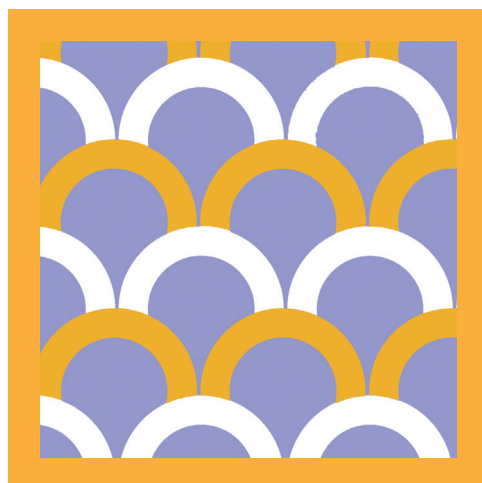
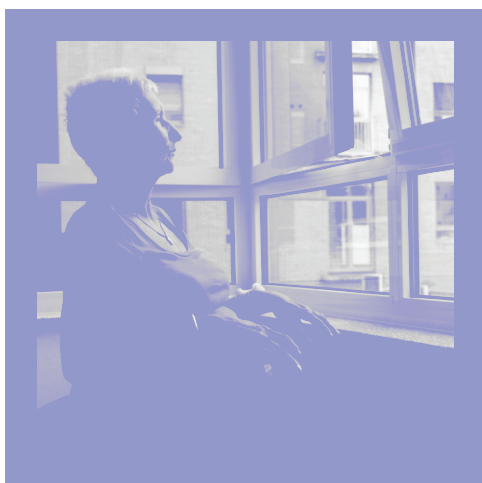
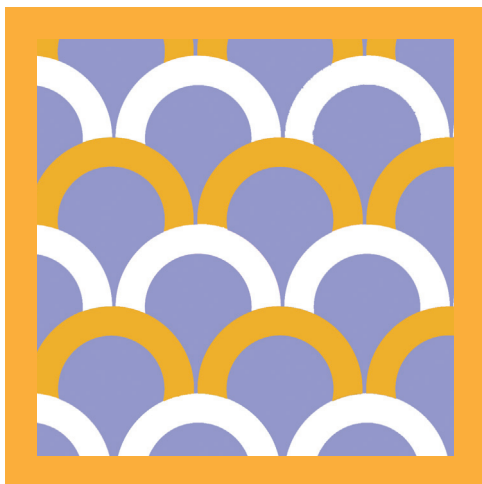


## Briefing paper on dementia advisors

Item type	Report
Authors	De Siún, Anna
Publisher	GENIO
Downloaded	5-Nov-2017 18:10:25
Item License	<a href="http://creativecommons.org/licenses/by-nc-nd/4.0/">http://creativecommons.org/licenses/by-nc-nd/4.0/</a>
Link to item	<a href="http://hdl.handle.net/10147/612491">http://hdl.handle.net/10147/612491</a>



# BRIEFING PAPER ON DEMENTIA ADVISORS

**Anna de Siún**

SEPTEMBER 2013

# Foreword

This is part of a series of papers that have been commissioned by Genio to provide accessible overviews of key areas relating to the development of dementia services. The paper explores the Dementia Advisor Role which focuses on the provision of information to people with dementia and their carers, the signposting of the dementia journey and the provision of support on that journey.

The evidence relating to the role of Dementia Advisors in other jurisdictions is provided, with an exploration of the impact of these roles on the person with dementia, carers and the health and social care system. The paper also describes some of the functions and tasks undertaken by the role and the learning which has resulted from the use of Dementia Advisors within both the international and Irish context.

This report informed the development of the National Dementia Strategy which is due to be published shortly.

I would like to acknowledge the work of Dr Anna de Súin in producing an excellent report and also the support of the Atlantic Philanthropies in funding this work.

**Dr Fiona Keogh**  
**Director of Research and Evidence, Genio**

# Contents

➤ Introduction	4
➤ Development of Dementia Advisor Roles Internationally	5
➤ Dementia Advisors in Ireland	10
➤ Research Evidence	12
➤ Conclusion	16
➤ References	18

# Introduction

Dementia is a term which describes a range of conditions which cause damage to brain cells, affecting memory, thinking, language, perception, mood and personality. It is a progressive condition, with deterioration likely to occur in all domains<sup>1</sup>. In 2009 it was estimated that there were 35.6 million people with dementia world-wide. By 2050 this figure will rise to over 115 million<sup>2</sup>. In Ireland it has been estimated that there were approximately 41,700 people with dementia in 2006. These numbers are projected to rise to between 140,580 and 147,000 by 2041<sup>1</sup>.

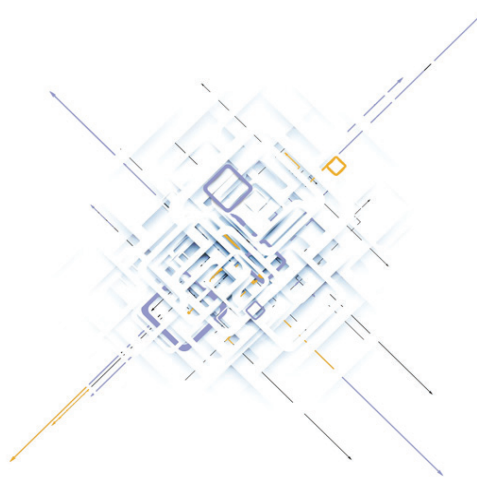
Traditionally dementia was defined in bio-medical terms with a focus on the physical causes and symptoms of the condition. Since the mid-nineties a range of alternative perspectives on dementia, psychosocial, socio-political and public health, have highlighted how this condition affects each person differently and the impact that contextual, environmental and cultural factors can have on the person's subjective experience of their condition<sup>1</sup>.

These multiple perspectives have resulted in a broader understanding of dementia and a recognition of the complex and changing needs of the person with dementia and their families/carers throughout the disease trajectory. In order to meet these needs a number of countries worldwide, including France, UK, Australia and Japan have developed national strategies for dementia. These strategies outline service developments that will not only meet the physical and medical needs of the person with dementia, but will offer a broad spectrum of care and support to both the person with dementia and their families/carers.

A common theme throughout these national strategies is the emphasis on the importance of information

provision and advice for people with dementia and their carers<sup>3</sup>. This is in direct response to findings from a number of consultations which highlighted the time-consuming and frustrating experience of many people with dementia and their carers in attempting to get the information they required due to the lack of coordinated information services<sup>4,5</sup>.

The majority of dementia strategies have chosen to address this information deficit through the development of dementia advisor roles. In brief the role of a dementia advisor is to work with individuals and their families, giving information and advice in a timely manner, directing people to appropriate agencies and supporting them throughout their journey. However the scope of this role varies between countries. The following section gives an outline of how the national dementia strategies in France<sup>6</sup>, England<sup>7</sup>, Scotland<sup>8</sup>, Northern Ireland<sup>9</sup> and Australia<sup>10</sup> are aiming to address the deficit in information and support to people with dementia and their families, particularly in the difficult period immediately after diagnosis.



# Development of Dementia Advisor Roles Internationally

France was the first European country to launch its National Dementia Strategy in 2001. Their third strategy 'Alzheimer and Related Diseases' ran from 2008-2012<sup>6</sup> and included sections dedicated to improving information and co-ordination of services. In order to meet the second objective of the plan 'Strengthening co-ordination between all actors involved', the strategy recommends the establishment of coordinator roles throughout the country. These coordinators work in a case management approach and have responsibility for producing a treatment and support plan for each individual and facilitating its implementation. They evaluate needs, provide liaison with care professionals, provide expertise to the person and their families in health and social fields, monitor the quality of care at home and guide families towards support structures to guard against crisis situations. The coordinators work in the newly established 'Centres for the Autonomy and Integration of Alzheimers Patients' (MAIAs), which were established to bring together the health sector and medico-social sector into a single point of information and support for the person with dementia and their families/carers. As soon as a diagnosis is given people with dementia are referred to their local centre by the memory unit of their primary-care doctor. The coordinator is therefore ideally placed to provide a link between social and healthcare teams to guarantee real multidisciplinary care. The Coordinators are also therefore key players in the strategy's 4th objective 'Improving access to diagnosis and care pathways'. While this coordinator role shares many similarities with the dementia advisor role, as defined in the previous section, it has a much broader remit and range of responsibilities. The strategy has been continuously assessed since its implementation and in 2012 it was found that a case

manager model for complex cases, integrated into the MAIAs, had a significant positive impact on the care pathway for people with dementia, with the average number of points contacted by a person before reaching the MAIA falling from 3.2 in 2009 to 1.3 in 2010<sup>11</sup>. A full evaluation of the 2008-2012 strategy was completed in 2013, and the recommendations from this report will be integrated into a fourth French Alzheimer Plan to be launched on World Alzheimer Day on 21st September 2013.

In 2009 the Living Well with Dementia: a national dementia strategy<sup>7</sup> was launched in England. Two of the strategy's seventeen objectives deal directly with the need for improved information and support. Objective 3 is for 'Good quality information for those with diagnosed dementia and their carers' while objective 4 aims to enable easy access to care, support and advice following diagnosis through the establishment of the dementia advisor role. The strategy recommends meeting objective 3 through; a review of existing relevant information sets; the development and distribution of good-quality information sets on dementia and services available of relevance at diagnosis and throughout the course of care; and local tailoring of the service information to make clear local service provision.

The dementia advisor role is being developed to provide a point of contact for all those with dementia and their carers, to provide information and advice about dementia and help signpost to additional services on an on-going basis. The report states explicitly that the dementia advisor would not duplicate existing case management or care. Rather their actions would be to identify what the

problems might be, and then to signpost and facilitate engagement with the specialist services that can best provide the person with dementia and their carers with the help, care and support they need simply and quickly. It is envisaged that in this way the dementia advisers would be in a position to work with the high numbers of people diagnosed with dementia in each area. At the end of an episode of care, individuals with dementia and their carers are not simply discharged from services, but instead continue to have access to the dementia adviser who contacts people pro-actively perhaps once or twice a year to check how things are. Advisers are located within the early diagnosis and intervention services being developed as part of the strategy. They work with both social care and health care services and are jointly commissioned by local health authorities and Primary Care Trusts. The strategy acknowledges that there is insufficient research evidence to recommend one particular model of care delivery, and therefore in 2009 dementia advisors were appointed in 22 demonstrator sites around the country, with an additional 18 demonstrator sites piloting different kinds of support networks for families and carers.

Scotland's National Dementia Strategy (2013-2016)<sup>8</sup> which was launched in June of this year outlines a link worker role which encompasses aspects of both the French and English models. They outline a national target for dementia whereby all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a Link Worker. The Link Worker will be responsible for building a person-centred support plan, working flexibly with each person with dementia and with the person's family and natural support networks.

In line with Alzheimer Scotland's '5 Pillars' model of post-diagnostic support, each link worker will have responsibility for; helping people to understand their illness and manage their symptoms; support people to retain their community connections and develop new ones; facilitate peer support networking, help plan for future decision-making and help in planning future support.

In 2011 Northern Ireland published its regional strategy 'Improving Dementia Services in Northern Ireland'<sup>9</sup> While the report acknowledges the findings from the 'Listening Well' report<sup>12</sup> regarding the need for better information and support services, the strategy does not recommend the establishment of dementia advisors in its action plan. Rather a series of recommendations involving the enhancement of current information services and resources are described, including; supplementing the GP information pack produced by the Dementia Services Development Centre with information on local services available; developing a service specification to inform commissioning for dementia care including information provision to individuals, families and carers; and developing practical, educational and psychological support for those caring for people with dementia. It is envisaged that this last recommendation would include a process to allow the knowledge gained by experienced carers to be shared with new carers. Responsibility for implementing these recommendations lies with the HSC Board and HSC Trust in collaboration with the Public Health Agency.

A similar approach to this information deficit is being adopted in the Australian national dementia strategy. Following on from their National Framework

for Action on Dementia 2006-2010, the Australian government have developed their 2013-2017 National Framework for Dementia, which is currently undergoing public consultation<sup>10</sup>. The strategy highlights the need for information and support for the person with dementia and their families post diagnosis. The report outlines how health professionals from a range of services play a pivotal role in providing information and understanding of the diagnosis and linking people with services to aid in the management of the condition. Many of their action therefore focus on the need to implement training and education programmes for GPs and Practice Nurses; support education and training for carers to enhance their skills and connect carers to essential information and support; and resource community based programs and initiatives to promote social engagement and develop dementia friendly environments. Like Northern Ireland, they do not recommend the introduction of additional staff/key workers in the area of dementia but rather are focusing on enhancing dementia support and information services through education and training of current service providers and service users.

Despite not being specifically detailed in the national strategy, dementia advisor services are being developed independently in many of the Australian territories. In New South Wales a Dementia Advisory Service has been established which is funded by Ageing, Disability and Home Care through the Ageing Grants Programme and the Home and Community Care Programme<sup>13</sup>. The service aims to; promote local awareness of dementia; provide information, education and support; and link people to assessment and support. In Central and North West Queensland dementia advisor posts are being

developed by Medicare Local, a not-for-profit organisation dedicated to delivering rural and remote primary health care services<sup>14</sup>. Not surprisingly, the responsibilities of the dementia advisor varies slightly between locations. All have the provision of information and signposting to services as central to the role and many also incorporate an element of raising awareness of dementia and building support networks in the community. In some areas the provision of counselling/support and delivering education and training to improve service delivery and build the capacity of services to meet the needs of client are included in the role. It is possible these roles may be supported by the government through its commitment to 'resource community based programmes and initiatives to promote social engagement and develop dementia friendly environments'

The key elements of each national strategy and the duties and responsibilities of the key people providing information are summarised in Table 1 overleaf.



Table 1: Key Elements of Dementia Advisor Type Roles Internationally

Country	National Strategy	Recommended Action	Key Responsibilities	Supporting Structures
France	Alzheimer and Related Diseases 2008-2012  4 <sup>th</sup> strategy due to be launched Sept. 2013	Establishment of Co-ordinator roles	<ul style="list-style-type: none"> <li>➔ Work to case management model</li> <li>➔ Produce and implement treatment and support plan for each individual</li> <li>➔ Evaluate need</li> <li>➔ Provide liaison with care professionals</li> <li>➔ Provide expertise to person with dementia and families in health and social fields.</li> <li>➔ Monitor quality of care at home.</li> <li>➔ Guide towards support structures to guard against crisis situations</li> </ul>	The co-ordinators work in the newly established 'Centres for the Autonomy and Integration of Alzheimer Patients' (MAIAs Patients are referred to the centre by the memory unit or primary care doctor after initial diagnosis. By working in the centre the coordinator has access to a range of health and social care practitioners. The primary care doctor is the coordinators direct contact for all aspects relating to healthcare. Specific training was provided to coordinators to support them in their role.
England	Living Well with Dementia  Launched 2009	Establishment of Dementia Advisors	<ul style="list-style-type: none"> <li>➔ Central point of contact for people with dementia and their families</li> <li>➔ Provide information and advice about dementia.</li> <li>➔ Signposting to additional services and supports.</li> </ul>	Located within the early intervention and diagnosis services developed as part of the strategy, advisors are ideally placed to receive referrals for people recently diagnosed with dementia. They do not duplicate the case management approach adopted by community mental health teams and outreach workers, which gives them time to work with the high volumes of people diagnosed each year.
Scotland	National Dementia Strategy 2013-2016	Establishment of Link Workers	<ul style="list-style-type: none"> <li>➔ Providing a minimum of one years worth of post-diagnostic support.</li> <li>➔ Building a person-centred support plan.</li> <li>➔ Working flexibly with person with dementia, their families and their natural support networks.</li> <li>➔ Help people understand and manage their illness</li> <li>➔ Help people manage their symptoms.</li> </ul>	Each Link Worker will have specific training in post-diagnostic support. In addition national training will be provided to help services understand and deliver the commitment to the service. This target is one of the NHS Scotland HEAT targets and resources have been developed to measure it appropriately.

Country	National Strategy	Recommended Action	Key Responsibilities	Supporting Structures
Scotland (cont.)			<ul style="list-style-type: none"> <li>➔ Support people to retain and develop their community connections.</li> <li>➔ Facilitate peer support networking.</li> <li>➔ Help plan for future decision making and support.</li> </ul>	
Northern Ireland	Improving Dementia Services in Northern Ireland: Regional Strategy 2011	Further development of current resources	<ul style="list-style-type: none"> <li>➔ Supplementing GP Dementia Information pack with information on local services available.</li> <li>➔ Developing a service specification to inform commissioning for dementia care, including; information provision to individuals, families and carers.</li> <li>➔ Developing practical, educational and psychological support for those caring for people with dementia.</li> </ul>	Responsibility for implementation of recommendations lies with HSC Board and HSC Trust in collaboration with the Public Health Agency.
Australia	National Framework for Dementia 2013-2017 Consultation Document	Strategy recommends further development of current resources. Dementia advisor roles being developed independently	<ul style="list-style-type: none"> <li>➔ Training and education for GPs, Practice Nurses and Carers</li> <li>➔ Resource community based programmes to promote social engagement and develop dementia friendly environments. <i>Dementia advisor roles</i></li> <li>➔ Provide information and signposting services.</li> <li>➔ Raising awareness of dementia in the community</li> <li>➔ Building support networks in the community.</li> <li>➔ Provision of counselling.</li> <li>➔ Delivering education and training to improve service delivery.</li> </ul>	The Australian Government and some State and Territory Governments have been identified as responsible for implementing the actions outlined in the National Framework. It is possible that the development of dementia advisor roles may be supported through the implementation of the action to 'support and resource community based programmes and initiatives to promote social engagement and develop dementia friendly environments'.

# Dementia Advisors in Ireland

While Ireland has not yet published its National Dementia Strategy, the recently published 'Creating Excellence in Dementia Care' (2012)<sup>1</sup> gives a comprehensive overview of current service provision in the country and makes a number of recommendations for improving services for people with dementia. The report highlights the need for 'more adequate timely post-diagnostic support services for people with dementia and their families' in Ireland today (p.70). Some support services which have been identified as necessary include; timely information on the condition for both the person with dementia and their families; assistance in accessing appropriate services and counselling. The Alzheimer Society of Ireland, following the model being developed in England, has appointed three part time dementia advisors in Dublin, Cork and Mayo, with a fourth position currently being recruited for the North Tipperary/East Limerick area. The Mayo dementia advisor post is funded through the Genio Community Action on Dementia in Mayo project.

According to the job description for the North Tipperary/East Limerick role, the main purpose of the dementia advisor role is to provide a local point of contact on an outreach basis for people who are concerned about their cognitive health and /or have a diagnosis of dementia and for their families and friends, at all stages of their journey, from diagnosis through to end-of-life. The role also has responsibility for working with statutory and independent organisations to improve their understanding and responses to the needs of people with dementia and their Carers. The role is designed to provide individual support at key transition times and to establish a range of activities such as training programmes and

peer-support groups to assist people in their journey with dementia.

In order to fulfil this role, dementia advisors build relationships with a range of service providers, including PHNs, GPs, memory clinics, discharge coordinators, Dept of Social Protection, Psychiatric community services, community care service providers, local nursing homes and day services. While this definition could be broadly applied to all dementia advisor roles in Ireland, the functioning of the role in each area differs slightly depending on the support structures and services in place locally. In Mayo the dementia advisor role was appointed as part of Community Action on Dementia in Mayo initiative and is an integral member of the memory clinic service, while in Dublin and Cork the dementia advisors are not part of the functioning of the memory clinics and those relationships are currently being developed. Informal communication with all three dementia providers provided a brief overview of the functioning of the service in each area. In all three areas the dementia advisors are finding that they are dealing with families and carers more frequently than with people with dementia, a finding reflected in local evaluations of dementia advisor roles in England. All advisors reported that they would like to have the opportunity to be more involved with working with people with dementia, ideally soon after diagnosis. The level of services available in each area differs significantly, with Mayo appearing to be the area with least resources available locally for the person with dementia and their families. All advisors feel that they are using a mixed method approach to providing their service, with an on-going case management approach being appropriate in some instances, while

at other times information and signposting is sufficient. In general the dementia advisors do not provide education or training to carers, though in one area the advisor is involved in establishing training programmes for carers as part of her other roles, and finds this an invaluable resource for her dementia advisor role. A key element highlighted by the dementia advisors already in post is the need for flexibility in the provision of the dementia advisor service as each person accessing the service will need different levels of information and support.

Despite the development of dementia advisor type roles in Ireland, England, Scotland and France, there is limited evidence as to whether investment in these types of services will produce benefits for people with dementia and their carers, while being affordable<sup>15</sup>. Results from some preliminary evaluations of local dementia advisor services in England suggest these roles may have a positive impact on quality of life and well-being throughout the disease trajectory, though there is undoubtedly a need for further research in this area. The following section looks at some of the research evidence available to date.

**“Dementia advisors build relationships with a range of service providers, including PHNs, GPs, memory clinics, discharge coordinators, Dept of Social Protection, Psychiatric community services, community care service providers, local nursing homes and day services.”**

# Research Evidence

In 2012 Corbett et al published the results from their systematic review of services providing information and/or advice to people with dementia and/or their caregivers<sup>3</sup>. They found that in general results indicated that dementia advisory and information services do offer some benefit on quality of life and prevention of neuropsychiatric symptoms in people with dementia. The authors note however that these results must be interpreted with caution as numerous studies involved additional services above and beyond the scope of an advisory service e.g. the inclusion of caregiver training. This is reinforced by the findings of the REACH programme which compared a multicomponent intervention with an information only advisory service and found the former to be much more effective<sup>16</sup>. The authors conclude that while there is reasonable evidence to support the value of advice and information services, it would need to be part of a multi-component service for optimal outcomes.

A systematic review of qualitative studies exploring experiences of community dwelling individuals with dementia and their carers around diagnosis and the transition to becoming a person with dementia was carried out in 2012<sup>17</sup>. The review highlighted how a diagnosis of dementia can have an enormous impact on a person's identity, leading to feelings of loss, anger, uncertainty and frustration. Studies show that people's reactions to a diagnosis of dementia tend to vary between individuals, both for the person with dementia and their families. This in turn impacts on attitudes towards information, with some people actively seeking information and others rejecting new knowledge. Therefore while information provision was seen as key in many studies, better information

and knowledge after diagnosis may not be the best solution as the individual's information needs are likely to change over time. The authors found that information provision needs to be ongoing, with flexibility in timing and format. They stressed that those with responsibility for making decisions around the delivery of services need appropriate expertise and training.

Another qualitative study carried out by Stirling et al in 2012 looked at professional and client perspectives on information flows and decision aid use<sup>18</sup>. They found health professionals had various attitudes regarding carers decision support needs and some groups were more likely to withhold 'realistic' information, or provide information only when they judged the person was ready, as too much information at one time may generate despair, depression or an inability to cope. However the researchers found in their interviews with carers that they wished to be seen as empowered individuals who needed realistic information in order to plan and decide about services. The authors argue that filtering important information about dementia can limit carers agency and require them to make relatively uninformed decisions about the future. The authors suggest that the provision of more emotional support together with disturbing information may be a more appropriate solution.

While no single conclusion can be drawn from this body of research, it draws attention to the complexity of the issues involved in providing appropriate and timely information to people with dementia and their families, and highlights that there is no one model of service provision which has been proven to be effective in this area. It was in recognition of

this that the National Dementia Strategy in England recommended the establishment of pilot, or demonstrator, sites for the implementation of the dementia advisor roles.

A national evaluation of the dementia advisors and peer support groups was carried out from 2010-2012 through the Healthbridge project<sup>19</sup>. The project assessed both service models in relation to;

- ➔ Influence on wellbeing of people with dementia and carers;
- ➔ Contribution to achieving the objectives of the National Dementia Strategy;
- ➔ How they work with other health and social care services;
- ➔ Identifying ways in which the new service models help people with dementia and carers.

While this research has been signed off by the Department of Health in England, it is currently with Ministers pending publication and is not yet available to the public. Another national evaluation which was commissioned in 2009 to assess the impact of dementia advisors on the quality of life of people with dementia was unfortunately discontinued in 2010 due to 'pragmatic difficulties combining the delivery of service and the research assessments'<sup>20</sup>. A number of evaluations of the dementia advisor services have been carried out locally, and results from evaluations carried out in Oxfordshire<sup>21</sup>, Worcester<sup>22</sup> and Westminster<sup>23</sup> are outlined below under three headings: Impact for Service Users, Organisations and Structures and the Experience of Dementia Advisors.

## Impact for Service Users

All three studies identified a range of benefits for service users through accessing the dementia advisor services. Benefits identified include:

- ➔ Greater confidence in the availability of support and their ability to access appropriate support when needed.
- ➔ Confidence in having someone to go to if concerns arise.
- ➔ Learning more about dementia and a range of issues associated with their needs.
- ➔ Understanding how to cope with problems associated with dementia.
- ➔ The opportunity to plan for the future, including financial and care issues.
- ➔ Support in applying for entitlements.
- ➔ Information about local support services
- ➔ Feeling supported emotionally

Some difficulties with the service were also identified during the evaluations. People tended to be less satisfied with the service where they were carers of a person with dementia who had been diagnosed with dementia for longer than 18 months before coming into contact with the service. In addition one report found that carers were less confident of the support available where they had only experienced contact by telephone, where ongoing contact had not occurred and where the person in receipt of the service was not linked into joined up services such as the Dementia Café.

Other difficulties reported included the low numbers of people with dementia themselves accessing the service, for the majority it is families and carers who are using the service. Another focus for the future is increasing engagement with harder to reach populations i.e. people who are living alone or housebound. Finally one report indicated that many services users are unaware of the service and what it can offer.

In general people valued the information given. However it was suggested in the evaluation that this information needs to be given with sensitivity and due regard to the needs of the person desiring the information as the experience can be overwhelming. This echoes the findings from the qualitative review carried out by Bunn et al (2012)<sup>17</sup> reported above. The evaluation also noted a lack of discussion around services which may contribute to the person's quality of life, which may indicate a lack in opportunities for meaningful engagement which is appropriately structured to meet the needs of people living with dementia and their families. This echoes the difficulties identified by some of the dementia advisors working in Ireland around lack of services designed to meet the needs of people with dementia in their locality. How the dementia advisor services in England integrated into existing service and support is explored in the section below.

## Organisations and Supports

Some dementia advisor services found that it took considerable time for referrals to be received, highlighting the effort required to establish the value of the service and enable other organisations to understand what their role is. Two of the evaluations emphasised a number of achievements regarding integrating the role into current services, including;

- Positive steps towards working more closely with the memory service and early information dementia services.
- Successful networking and partnership working with a range of agencies and professionals, including the Carers Network, Admiral Nurses, Community Mental Health Teams, Consultant Psychiatrists, Liaison Nurses and Social Workers.
- Enabling people with dementia and their families to access the service appropriately.

As mentioned above, a number of difficulties in establishing the service were encountered at the initial stages. The reports highlighted some areas where work still needs to be done in regard to:

- Defining protocols for working with the memory services and early interventions services to avoid duplication of effort.
- Increased understanding of the dementia advisor role and how they fit into established care pathways.
- Raising awareness of the dementia advisor role amongst groups and the wider public.

- Aligning the service with primary care.
- Increasing the availability of services to enable people to live well with dementia.

Therefore while a lot of work has been done to allow the dementia advisors to work well with more established services, there is additional work needed to ensure that the dementia advisor role integrates seamlessly with existing services to enhance the experience of the person with dementia when accessing support and health services.

**“Some dementia advisor services found that it took considerable time for referrals to be received, highlighting the effort required to establish the value of the service and enable other organisations to understand what their role is.”**

## Experience of Dementia Advisors

The dementia advisors in the three areas evaluated were all interviewed and identified a number of key aspects and responsibilities in their role. These included:

- Being alongside the person living with dementia and their family on their journey. This meant giving time and space to the carer to explore how they are feeling and what the diagnosis means to them, space to voice the reality of the situation and talk about just how difficult things are at times and affirmation of what the carer is doing.
- Providing a named contact so the person with dementia and carer knows they are not alone.
- Carrying out an assessment of need to determine needs regarding information and advice, signposting and support.
- Providing information and advice which is sensitively tailored to the expressed needs of the person in receipt of the service. Information needs range from:
  - Benefits and financial concerns
  - Dealing with incontinence
  - Coping strategies for specific issues (e.g. preventing falls, behaviours that challenge)
- Networking and developing partnerships with key agencies and individual professionals.

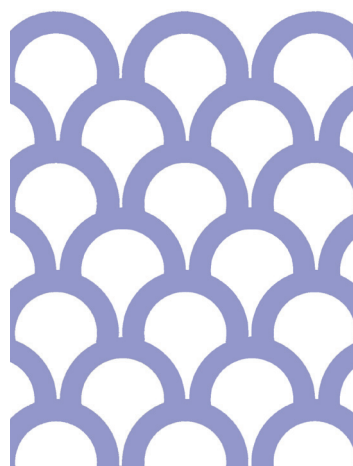


- ➔ Developing local knowledge so that signposting activities can be carried out effectively.
- ➔ Reducing stigma.
- ➔ Identification of unmet need.

From the range of responsibilities identified as necessary in the dementia advisor role, it is apparent that dementia advisors need a broad range of knowledge, skills and personal attributes such as empathy, resilience and creativity to fill this role effectively. The dementia advisors from all services highlighted the importance of flexibility in service provision to ensure the unique needs to each service user are met where possible. The dementia advisors also identified a number of barriers they have encountered in establishing their service. These included:

- ➔ Lack of definition and structure of the dementia advisor role.
- ➔ Lack of preparedness of the area to receive a dementia advisor.
- ➔ Difficulties related to working in isolation, particularly the need to remain objective and the emotional experience of providing a service to people with complex and emotionally demanding needs.
- ➔ Risks involved in home visits, particularly where the dementia advisor is working alone.
- ➔ The receptiveness of other services to the role.
- ➔ Lack of services to enable people to live well with dementia.

The facilitators to overcoming these barriers included; effective management and supervision, partnership working, achieving clarity concerning the nature and boundaries of the role, being outside of statutory service provision and preparation of the area. While these evaluations give an insight into some of the achievements and difficulties of the dementia advisor services, further evaluation is necessary to explore the impact of these services on people with dementia and their families quality of life, self-esteem, coping and ability to remain at home. It must also be emphasised that while these three evaluations give insight into the dementia advisor role, they represent a very small percentage of the number of roles established in England since 2009. It is hoped that the results of the Healthbridge evaluation will help to answer some of the above questions and give a clearer picture of the dementia advisor role from a national perspective.



# Conclusion

Preliminary evidence does support the development of dementia advisor roles as an efficient way of providing the information and support so clearly needed by people with dementia and their families and carers. However, defining the role can be difficult as it is unclear what components need to be present to ensure it is as efficient and effective as possible. The provision of information around dementia, including advice on finances, entitlements, capacity, planning for the future and coping strategies is an essential element in this role. The timing of the provision of this information is an area which some report needs to be done sensitively and appropriately, while others argue that realistic information needs to be given to carers as soon as possible in conjunction with good emotional support. Signposting to appropriate services, both local and national, is also reported to be necessary. However the degree to which signposting can be effective relies heavily on the number and types of services available to enable people to live well with dementia.

While information and signposting is vital, research evidence suggests that this type of intervention is more effective when combined with other components. It is clear from both local evaluations in England and informal communication with dementia advisors in Ireland that on-going support will be needed by some people and their families. This can include emotional support through giving people space to voice their fears and concerns around a diagnosis, coordinating services on behalf of the person with dementia, developing individual support plans and being a point of contact when circumstances change.

Integral to the role of the dementia advisor is the need to build strong linkages with statutory, voluntary and private health and social care providers. To facilitate this process there is a need for a clear definition of the role so as to avoid confusion and duplication of effort and ensure appropriate referrals can be made from multiple sources. However in order to provide a service that is tailored to the individual needs of its clients there is clearly also a need for flexibility within the role. Dementia advisor roles cannot be developed in isolation but need to be part of the innovative development of dementia care in Ireland today, acting as a bridge for the person with dementia to find the support and information they need at each point in their journey.

# References

1. Cahill S, O'Shea E & Pierce M. (2012) Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy, IDC's Living with Dementia Research Programme, School of Social Work and Social Policy, Trinity College, Dublin, Irish Centre for Social Gerontology & National University of Ireland, Galway.
2. Alzheimer's Disease International (2009) World Alzheimer Report 2009. London: Alzheimer Disease International. Available online [www.alz.co.uk/research/files/WorldAlzheimerReport.pdf](http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf).
3. Corbett A, Stevens J (2012) Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International Journal of Geriatric Psychiatry*. 27:628-636.
4. Alzheimer's Society (2009) The Information Challenge: Findings, Think Public.
5. Alzheimer's Society Ireland (2011) National Dementia Summit 2011 Report.
6. National Plan for 'Alzheimer and Related Diseases' 2008-2012. Available online <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/France?#fragment-1>.
7. Living Well with Dementia: A National Strategy. Available online [www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy](http://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy).
8. Scotland's National Dementia Strategy: 2013-2016. Available online [www.scotland.gov.uk/topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316](http://www.scotland.gov.uk/topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316).
9. Improving Dementia Service in Northern Ireland: A Regional Strategy. Available online [www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf](http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf).
10. Consultation Paper: National Framework for Action on Dementia. 2013-2017. Available online [www.health.gov.au/internet/main/publishing.nsf/content/dementia\\_nfad2013-2017](http://www.health.gov.au/internet/main/publishing.nsf/content/dementia_nfad2013-2017).
11. Plan Alzheimer 2008-2012: Implementation as of 1st February 2012. Available online [www.plan-alzheimer.gouv.fr/IMG/pdf/Plan\\_Alzheimer\\_4th\\_anniversary\\_2.pdf](http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_4th_anniversary_2.pdf).
12. Alzheimer Society (2009) Listening Well: People with dementia informing the development of health and social care policy.UK: London Available online [www.alzheimers.org.uk](http://www.alzheimers.org.uk).



**Disclaimer:**

The views expressed in this report should not be taken to represent the views of Genio, the Genio Trust or of its funders; the Atlantic Philanthropies, the Department of Health and the Health Service Executive. Any errors or omissions are the responsibility of the author.

© GENIO, 2013

Genio, Marlinstown Office Park,  
Mullingar, Co. Westmeath, Ireland.  
Tel: +353 (0)44 9385940  
Email: [info@genio.ie](mailto:info@genio.ie) Web: [www.genio.ie](http://www.genio.ie)

