


Worcestershire Health and Care   
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# *Living Well With Young Onset Dementia;*

**Consultation with younger people with Dementia  
and their families about their experiences and needs  
in Worcestershire.**

Jenny La Fontaine, Young Onset dementia Development Officer, February 2014

Jenny La Fontaine

Young Onset Dementia Development Officer

Early Intervention Dementia Service

F Block

Kidderminster General Hospital

Bewdley Road

Kidderminster

Worcestershire

DY11 6RJ

Tel 01562 828894

[Jenny.lafontaine@hacw.nhs.uk](mailto:Jenny.lafontaine@hacw.nhs.uk)

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## **Glossary of Terms**

**Admiral Nurses:** Admiral Nurses are mental health nurses specialising in dementia. Admiral Nurses work with family carers and people with dementia, in the community and other settings. Working collaboratively with other professionals, Admiral Nurses seek to improve the quality of life for people with dementia and their families and carers. They use a range of interventions that help people live positively with the condition and develop skills to improve communication and maintain relationships. There are currently 6 Admiral Nurses within Worcestershire, covering the whole county. Admiral Nurses can be contacted on 01386 502032

**Als Café:** An Al's Café is a social gathering of people who live with and are affected by Dementia of all forms. The emphasis of Al's Café's is to have opportunities to socialise and meet with others who have similar experiences. Café's are often highly individual in what they do for their members, but commonly they include opportunities to increase knowledge, share experiences and strategies for coping. People are welcome to attend Al's Café's as and when they feel they need to. There are currently a number of Al's Café's for younger people living with dementia and their families held in Malvern, Redditch, Kidderminster and Worcester.

**Dementia Advisers:** Dementia Advisers are professionals who act as a named contact for people living with dementia and their families and carers throughout their journey with dementia. They provide information and advice that is tailored to the needs of the person and their family. They will also provide information concerning services that the person and their family might access in relation to their needs. Dementia Advisers are employed by AgeUK in Worcestershire and can be accessed by telephoning 0800 008 6077

**Onside:** Onside is a Worcestershire based charity that is involved in supporting adults who may be disadvantaged or vulnerable. They provide specific support for younger people with a diagnosis of dementia. This service involves one to one support to enable the younger person to engage in activities that are meaningful to them on a regular basis. Onside can be contacted on 0844 248 9248.

**Penderels Trust:** Penderels Trust offers advice, guidance and practical solutions to enable people with disabilities and older people to live independently in their own homes, to achieve their goals in life and to help them play an active part in their community. They enable people who have been assessed as requiring a personal budget or direct payment to manage the processes involved including budget management, employment and selection of care agencies. Penderels Trust can be contacted on 0845 606 0361

## Introduction

The Worcestershire Dementia Strategy (2010) estimates that there are currently around 160 younger people (those aged 65 and below) with a diagnosis of dementia living in the county. These figures may be an underestimate, as it is widely recognised that it is difficult to establish the exact numbers. So while prevalence is estimated at 2.2% it is possible that the prevalence is as much as three times higher than this (Dementia UK, 2007).

While the numbers of younger people living with dementia are significantly smaller than those developing dementia in later life, dementia at a younger age brings particular challenges for the person, their family and for the services that support them. These challenges include;

- Difficulty with achieving a diagnosis;
- Experiencing less common forms of dementia;
- Managing challenges associated with the time of life at which it occurs, including work and financial obligations;
- The impact upon family members including spouses, partners, adult and dependent children and young people;
- Access to need and age appropriate support and services

A multi-agency subgroup of the Worcestershire Dementia Care Planning Group, has sought to identify and explore ways of addressing the needs of younger people with dementia and their families in Worcestershire. Through this group, the role of young onset dementia development officer was established and appointed to in 2013. A number of key actions are associated with this role including;

1. Identifying the need for services through consultation with all stakeholders including younger people with dementia and their families and drawing upon the work that has already been completed, to identify what works and what doesn't work
2. Engage with younger people with dementia and their families as active partners in the development and implementation of the care pathway
3. Working closely with the Joint Commissioning Unit (JCU) and stakeholders from Health, Social Care and the Third Sector to identify and develop an integrated care pathway for young onset dementia

During November and December 2013, to achieve the first of these actions, consultation occurred with younger people with dementia and their families concerning their needs and experiences. Six group consultation meetings were held across different locations within Worcestershire with younger people with dementia and their families. A further 14 meetings were held with younger people with dementia and their families at their home.

This report brings together the contributions of younger people with dementia and their families concerning the answers to two key questions;

- What is important to you to live your life well/ as you would wish to
- What help and support would be needed to enable you to achieve this

Additionally, many of those who attended also contributed their experiences and concerns in managing to live with dementia.

A total of 41 families (which includes a number of younger people with dementia) contributed their perspectives to this report, and have had the opportunity to review it and add any further contributions as appropriate. It is important to note that due to the difficulties associated with diagnosis and other factors, it is possible that some younger people with dementia and their families are not linked into services and therefore were unaware of these events. Furthermore, that the majority of contributions were from families who have lived with dementia for some time, and includes those whose diagnosis was delivered before some services were established, including Dementia Advisers, the Early Intervention Dementia Service and county wide provision of Admiral Nursing.

This report is structured to highlight the concerns, needs and experiences expressed of younger people living with dementia and their family members at each stage in their experience of living with dementia. It is therefore broken down into three sections, addressing;

- The early experience of symptoms leading to and including the diagnosis of dementia and support following diagnosis;
- Living with dementia and;
- Increasing need for care at home, in hospital or in a care home

A number of key themes emerged from the consultation concerning the experience of dementia at a younger age. The needs identified include those expressed by people with dementia where possible, and their family members. It is important to recognise that the needs expressed may vary within families and between each family. Accordingly, where differences are expressed, all perspectives are included.

This process of consultation is only the beginning. We sincerely hope that it provides the foundation for ongoing consultation, involvement and engagement with younger people living with dementia and their families as we seek to identify and develop the support that is offered.

## **The early experience of symptoms leading up to a diagnosis of dementia and support immediately following diagnosis**

### ***Concerns and experiences***

The challenges and experiences associated with developing symptoms which ultimately lead to a diagnosis of dementia reflect a number of distinct themes. These were;

#### ***Being believed and feeling understood***

When first recognising that something was wrong, many participants, (both younger people with dementia and family members) highlighted that they found it difficult to convince others that something needed to be done. Although some emphasised that the health professional they approached was supportive and proactive, others found it to be a struggle to be believed, and felt with hindsight, that there is a lack of knowledge and understanding of the possibility that dementia might occur in people below the age of 65 within Primary Care. Where difficulties with convincing health professionals that action was needed occurred, this caused frustration and distress, with some feeling that their concerns were dismissed. Some participants highlighted that the symptoms being experienced were discounted by those they approached for help as stress, relationship difficulties, the menopause or failing at work. Such actions resulted in long periods of time before referrals through to appropriate services for assessment occurred.

#### ***Achieving a timely diagnosis***

Once a referral had been made, participants found that they were likely to be referred to a range of services for assessment and diagnosis, including Neurology, Adult Psychiatry, Older Adult Psychiatry, and the Early Intervention Dementia Service. Some were also referred out of county to other services and a few found that in order to get answers they needed to pay for a private healthcare assessment. Some participants highlighted that they had experienced a positive process of assessment and diagnosis, from a knowledgeable and informed professional and/ or service, and felt supported during this process. Additionally some of these participants felt that even where answers were not immediately forthcoming and consultation with others was required, explanations and support were given. However, many more found that long periods of time with little in the way of explanations or support ensued, followed by referrals on to other services and further delays in being seen and assessed. Consequently, a number of those contributing to this report emphasised delays of at least a year and frequently considerably longer before they received a diagnosis.

#### ***Feeling supported through the process of assessment and diagnosis***

Many participants highlighted the level of stress and distress that they and their families experienced during this period of uncertainty. The prolonged period of not knowing often



contributed to or resulted in, financial insecurity and loss of employment and sometimes difficulties within the family or with relationships. While some people reflected that they had experienced a lot of support during the diagnosis from knowledgeable professionals, many did not, and described being given little or no information about the diagnosis or its consequences for them. Following diagnosis, some described being directed to a leaflet or a website or leaving following diagnosis with nothing at all. Others described being given information which did not assist them to link in with existing services, for example not having explanations that the Alzheimer's society provides support to people who have other forms of dementia. Support following diagnosis was also a concern to those who were referred out of county to other services or to private health care providers as they were not necessarily given information or supported to link in to services within Worcestershire following this assessment and diagnostic process.

*Having access to knowledgeable staff immediately following diagnosis who provide timely and appropriate information and support*

Participants emphasised the challenges experienced following a diagnosis of young onset dementia. The diagnosis was often unexpected, as people were not necessarily aware that it was possible to get dementia at a younger age. The stigma associated with dementia was a concern for them and their families. Accessing the right sort of information to help them understand was difficult, for example the internet was described as a source of information but not always a helpful one, as the information was not tailored, could be overwhelming and frightening. Furthermore, as less common forms of dementia were more likely to occur at a younger age, finding the right sort of information and support was often found to be more difficult. The need for assistance with financial planning, employment and learning to cope with the aftermath of the diagnosis was frequently cited as important but not often available. Furthermore, although small in number, some participants had dependent young people or children to consider and found that the impact upon them was considerable and that proactive support for them was not forthcoming.

Finally, although some had found the support offered from specialist services such as EIDS to be very helpful, the withdrawal of that support following a period of intervention was keenly felt as a loss, particularly if support following this withdrawal was not forthcoming. A number of the participants talked about their need for continuity of staff to call upon and to be supported by, following their diagnosis.

*The early experience of symptoms leading up to a diagnosis of dementia and support immediately following diagnosis*

Key Theme	Needs	Things that will help me/ us achieve these needs
<p><b>To understand and have an explanation about the symptoms being experienced</b></p>	<ul style="list-style-type: none"> <li>• To be believed/ taken seriously with the concerns I/ we have</li> <li>• To be referred to a service that has knowledge and expertise in dementia in younger people</li> <li>• To be helped to make a decision about whether I want an assessment</li> <li>• To have an assessment of my symptoms by knowledgeable professionals</li> <li>• To have an explanation for my symptoms</li> <li>• To feel supported through the process of assessment and diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>• Challenge the public perception of dementia, challenge stigma</li> <li>• GP's and Nurses who know about what is available, understand about dementia in younger people and can refer me to the right service</li> <li>• Not to be pushed from pillar to post, one service that provides assessment and diagnosis for younger people with suspected dementia</li> <li>• Someone to talk with about the feelings I/we have about my symptoms and the effect these are having</li> <li>• To be referred to a service and to be responded to without having to chase the referral</li> </ul>
<p><b>To have a diagnosis when the time is right for me and my family</b></p>	<ul style="list-style-type: none"> <li>• To have an accurate diagnosis, the truth, from knowledgeable professionals</li> <li>• To adjust to the emotional impact of the diagnosis of dementia</li> <li>• To understand what is happening and what might happen, depending on how much I/ we want to know</li> </ul>	<ul style="list-style-type: none"> <li>• To have a diagnosis from knowledgeable and informed professionals</li> <li>• To have someone to talk with about the feelings I/we have about the diagnosis and the impact on our lives</li> <li>• Information that is comprehensive and addresses diagnosis, financial and legal help, how to access different systems and services when needed</li> <li>• One single place where this information can be provided, so I/we don't have to search for it</li> </ul>

Key Theme	Needs	Things that will help me/ us achieve these needs
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**To begin the process of living my life as I wish to**

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• To be respected</li> <li>• To be able to do the things that make life meaningful for me</li> <li>• To have purpose in life</li> <li>• To be able to talk about my feelings if I need that</li> <li>• To have enough information to help me to cope</li> <li>• To remain independent</li> <li>• To be financially secure</li> <li>• To be able to meet my everyday needs</li> <li>• To maintain the relationships that are important to me</li> <li>• To develop strategies for managing the difficulties I experience</li> <li>• To continue to be part of my community</li> <li>• To feel that I am not alone</li> <li>• To be able to go out independently</li> <li>• To have fun!</li> <li>• To feel supported and to know where to get help when I need it.</li> </ul> | <ul style="list-style-type: none"> <li>• Services to remain involved for as long as I need them</li> <li>• Opportunities to talk with others who have a diagnosis and their families and to learn from each other, both with my family and as an individual in my own right</li> <li>• Contact numbers for important organisations, e.g. a single card with primary numbers</li> <li>• A pathway that tells you what is going to happen and who will do what</li> <li>• Help from professionals so that I can continue to do the things I value</li> <li>• Using new technologies to keep in contact with others</li> <li>• Support to make financial plans and to address advance plans including Lasting Power of Attorney</li> <li>• Support to remain in work if possible</li> <li>• Courses providing information on a range of topics related to my needs that are flexible and respond to my circumstances</li> <li>• Continuing to do things I enjoy and finding new things to do</li> </ul> |
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Key Theme	Needs	Things that will help me/ us achieve these needs
<p><b>That my Family Members/ significant others needs are met too</b></p>	<ul style="list-style-type: none"> <li>• To understand what is happening</li> <li>• Emotional support to adjust to the implications of the diagnosis</li> <li>• To have financial security</li> <li>• That children and young people have information and support</li> <li>• To have separate time to consider our own needs</li> <li>• To feel that we are not alone</li> <li>• To feel supported</li> <li>• To know where to get help when we need it</li> </ul>	<ul style="list-style-type: none"> <li>• Information that is comprehensive and addresses diagnosis, financial and legal help, how to access different systems and services when I need it</li> <li>• A pathway that tells you what is going to happen and who will do what</li> <li>• Courses that are flexible and respond to my circumstances</li> <li>• An Admiral Nurse</li> <li>• Opportunities to meet with others who live with dementia and their families, together with my relative and separately to meet our own needs</li> <li>• Support for children and young people that helps them cope emotionally and provides them with age appropriate information and helps me to help them</li> <li>• Support to remain in work</li> <li>• Having guidance to manage family difficulties</li> </ul>

## **Living with young onset dementia**

### ***Concerns and experiences***

A number of concerns initially highlighted in the period leading up to and including diagnosis continued into learning to live with dementia and became significant challenges for many of the people attending the consultation events.

### ***Living with dementia at a younger age***

Participants described feeling that because the difficulties associated with experiencing dementia were not immediately apparent and that as developing dementia at a younger age is not expected, assumptions were made about what a person could do. For example some families spoke about difficulties in getting financial support in the form of benefits. They felt that because the person did not have physical disabilities it was assumed that they could manage independently and therefore did not need financial assistance. This has had significant implications for managing everyday life in the local community and in maintaining relationships and valued activities. While some people attending felt that they had found strategies that made a difference, for example negotiating with local shops so that a person with dementia can continue to shop there, many more people felt isolated, misunderstood and unable to engage in everyday activities as a consequence. Family members also identified the struggle they experienced emotionally and practically in understanding how to help and how to negotiate the different systems in order to get support. Managing everyday needs was made considerably more difficult as systems for claiming financial entitlements were experienced as complex and overwhelming. Some participants described that the process of assessment was demeaning and others found that repeated claims had to be made before benefits were awarded. Some participants felt that much of this was due to a general lack of knowledge of the impact and experience of living with dementia at a younger age. Of particular concern was the importance of doing things to maintain independence for as long as possible, but often participants felt that support to do this was largely unavailable to them.

### ***I should not be invisible***

Many of the people who attended the consultation events described feeling that they were left alone to cope with the consequences of the diagnosis, and its impact upon their lives. Additionally, they felt that their needs were largely unrecognised, frequently because of a lack of understanding and awareness.

Family members who participated emphasised an on-going lack of information and support in order to cope, also feeling that they were invisible. One person described this as 'working blind', not knowing who to go to and what you can ask for. The difficulties of supporting a younger person with dementia were emphasised because they were told either that the

person was under 65 and therefore not eligible for services for people with dementia, or that they had dementia and were therefore not eligible for services designed for adults of working age. Some participants described that this was made worse because they felt they were expected to know what was available and how to access it and that services didn't make this information easily available. Some family members felt that being known and knowing services early in the experience of dementia would help the person with dementia to adjust and build trusting relationships with others early on. The absence of these relationships often caused challenges later on when care was needed, and the person with dementia rejected such support because the people were not familiar to them.

### *I still want a purposeful and meaningful life*

The younger people with dementia who contributed to the consultation and their families stressed the importance of being able to remain in work for as long as possible or to engage in voluntary work. Some younger people with dementia had found voluntary work to be fulfilling and helpful. Where this was not possible, many expressed the desire to have opportunities to engage in activities that were meaningful to them. However this was felt to be difficult to achieve, for a number of reasons;

- The person with dementia had lost their job or had been made redundant, often as a consequence of the difficulties experienced
- They could not travel independently on public transport
- Loss of ability to drive
- They needed support within these activities to maximise their abilities and manage the challenges they experience
- Lack of availability of local relevant and appropriate activities

For many younger people with dementia, this has meant that they have had to increasingly rely on family members, thus reducing the opportunity for independent time as well as time together. Independent time is viewed by some as a necessary and important contributor to their wellbeing. The change in roles that this loss of independence created was seen as a difficult consequence of living with young onset dementia.

In regard to service provision for people to engage in meaningful activity and to live well, Al's Way (the service provided before Onside [see glossary]) was described as particularly helpful by many attending. The benefits were cited as having the same workers, who had been matched with the person with dementia and continued to support them, even when personal care needs were increasing. Furthermore, that they provided assistance to engage with the Al's Café and supported regular reviews of the person's needs. The holistic nature of this provision, providing a sense of being held and a sense of community was powerfully reflected in the perspectives of the people who were involved in the consultation. The change in the provider and the way in which the service was provided was experienced as a profound loss by some of those who had received a service from Al's Way.

The need for on-going and structured meaningful activity that was tailored to the person's needs was described as limited in availability. Although some of this is provided by Onside Mentors, not all participants knew about this service. It was felt that not enough local and tailored provision was available to meet the needs of younger people with dementia. Participants said that they would not necessarily want to, nor would enjoy a service that was predominantly provided for people who were significantly different in age and life experiences than themselves; they wanted to be able to engage in activities with their peers that reflected their lifestyles and experiences. This was particularly an issue for those younger people who were still very active and able and wished to continue to be so.

### *Support from Peers and Specific Services*

Many of those family members attending identified that the main source of reliable support for them was from their peers. They emphasised how important learning from each other had become, particularly as some felt that professional support was not available. They described finding out about Carer support and Al's cafés by 'accident' but then really valuing the opportunities they created to learn strategies and how to access help. However some people described difficulties with the opportunities for peer support, not all felt able to attend meetings held in the evenings, due to the impact of dementia upon wellbeing at night, or because of their work and family commitments or because of difficulties with distance and travel. Furthermore, some found contact with too many people overwhelming.

Support from various services including Admiral Nurses and Dementia Advisers [see glossary], and individual professionals from statutory services were found by some to be valuable where they were available. However some of the participants did not know about Admiral Nursing and Dementia Advisers and how they could access them and some reflected upon difficult experiences in engaging with statutory services.

### *Non-stigmatising support for children and young people*

In a small number of families, young people and children are living with the person with dementia. The impact of dementia in a parent was felt to be significant, and that support is needed to help them to manage. Concerns expressed included that the experience impacts upon education, family life and friendships and ultimately life chances if it is not addressed proactively. One family identified that their children were expected to deliver personal care because they were on school holidays and as a consequence, care at home was delayed until they returned to school. The family did not feel this was an appropriate expectation of a young person. Additionally participants felt that while support is available from such services as educational psychology or child and adolescent mental health services, the child or young person may find these stigmatising and would not be willing to participate. Therefore they felt that thought needs to be given on how to support children and young people effectively.

<b>Key Themes</b>	<b>Needs</b>	<b>Things that will help me/ us achieve these needs</b>
<b>I need to have a purpose in my life, I want to carry on as normal for as long as possible</b>	<ul style="list-style-type: none"><li>• I need to do things that give me a sense of purpose and achievement</li><li>• I need to maintain my self-respect</li><li>• I want to have choices about what I do and what is important to me</li><li>• I need to have accessible means of getting to work/ activities that I enjoy</li><li>• I want to have fun!</li></ul>	<ul style="list-style-type: none"><li>• To be able to stay in work for as long as possible</li><li>• To do voluntary work</li><li>• To have support to engage in the activities/ work so that I can continue to do them for as long as possible</li><li>• To be able to continue to drive for as long as possible</li><li>• To have affordable and accessible transport to get to activities with support to use this if I need it</li><li>• Local support that works for me and my family</li><li>• Holidays</li><li>• Opportunities to be creative, e.g. art activities</li><li>• That when I need it, I have a supporter to help me to engage in these activities who is able to remain with me as my needs change and I need more help</li></ul>
<b>I need to feel that I am of value</b>	<ul style="list-style-type: none"><li>• I want to be treated with respect and not spoken down to</li><li>• I need to maintain my independence for as long as possible</li><li>• I want my views and needs to be heard and responded to</li><li>• I want to maintain the roles I have in life</li><li>• I need to feel that I am not alone</li><li>• I need to be heard and believed</li><li>• I need peace of mind and heart</li></ul>	<ul style="list-style-type: none"><li>• Others understand the needs of younger people with dementia and their families, including communities and professionals</li><li>• Professionals who don't make assumptions and try to understand our perspectives</li><li>• Professionals and others who understand and are able to support me and my family, and refer on for support which meets our needs</li><li>• Individualised and person centred care, each person and family is different</li><li>• 24 hour helpline, opportunity for 'webchats' with others in a similar position</li></ul>



Key Theme	Needs	Things that will help me/ us achieve these needs
<p><b>I need to maintain the relationships I have with people I care about</b></p>	<ul style="list-style-type: none"> <li>• I want to be able to continue to have relationships with those people who are important to me</li> <li>• I want to have a normal family life</li> <li>• I need to share with others who understand my experiences</li> </ul>	<ul style="list-style-type: none"> <li>• Support to help me to maintain contact with the people who are important to me</li> <li>• Information and support to the wider family so that they understand and maintain their relationships with me</li> <li>• Time with others who understand and are in a similar position separately from my family and together with them as needed</li> </ul>
<p><b>I need to feel secure</b></p>	<ul style="list-style-type: none"> <li>• I want to be financially stable</li> <li>• I want the local community and services in that community to support me to remain independent</li> <li>• I want my life to run as smoothly as possible</li> <li>• I need structure and routines that help me to cope</li> <li>• I need to have people around me who understand me and my routines</li> </ul>	<ul style="list-style-type: none"> <li>• Benefits advice and support to complete forms</li> <li>• To be able to work out how to manage the DWP process for claiming benefits, including that they are responsive to my difficulties and I am supported to make claims</li> <li>• Dementia friendly communities</li> <li>• Support that is easily accessible so I don't have to 'hit rock bottom' before help is provided</li> <li>• Adaptations to my home that make it possible for me and my family to cope, without having to negotiate complex planning systems</li> <li>• Professional Carers who understand my needs and are able to support me</li> <li>• Discreet ways of helping others to understand my needs if I am having difficulties</li> <li>• Services that are linked together and communicate with each other</li> </ul>

Key Theme	Needs	Things that will help me/ us achieve these needs
<p><b>I need to be well</b></p>	<ul style="list-style-type: none"> <li>• I would like to feel well emotionally and physically</li> <li>• I would like to be supported to remain as well as possible</li> <li>• I need to understand what is happening to me and to have ways of managing these challenges</li> <li>• I need to be able to sleep well</li> </ul>	<ul style="list-style-type: none"> <li>• To have clear and accurate information that can be accessed from one place</li> <li>• A website where information about benefits etc. is available, along with the opportunity to post or share experiences with others</li> <li>• Family doctors who provide regular support and appointments, with the same doctor for continuity, who provides proactive monitoring to pre-empt possible difficulties</li> <li>• A service that understands about young onset dementia and is knowledgeable about our needs, who provides advice, information and assistance to manage my condition</li> <li>• That my ability to travel independently is assessed and managed appropriately to ensure I can travel safely</li> </ul>
<p><b>It's important to me that my family and the people I care about are OK</b></p>	<ul style="list-style-type: none"> <li>• I want my family to have the support they need</li> <li>• We may benefit from time apart from each other as well as time together</li> <li>• We need information and support to understand what is happening</li> <li>• We need to know who to approach for support and where to go when this is needed</li> <li>• We need to be able to sleep well</li> <li>• We need to have fun</li> <li>• We need to feel that we are not alone</li> <li>• We need to be heard and</li> </ul>	<ul style="list-style-type: none"> <li>• To have clear and accurate information that can be accessed from one place including information about services</li> <li>• A website where information about benefits etc. can be posted, along with the opportunity to post or share experiences with others</li> <li>• 24hour helpline</li> <li>• Having guidance to manage family needs and issues</li> <li>• Accessible and responsive support so I don't have to 'hit rock bottom' before help is provided</li> <li>• Support for the younger person with dementia that is beneficial to their wellbeing and means that we can have time to ourselves as well</li> </ul>

- 
- believed
- Children and Young People need to understand and be able to cope with the experience of a close relative with young onset dementia
  - We need peace of mind and heart
  - We need to feel that we are cared about
- Support to be available at weekends and holidays
  - Others are helped to understand the needs of younger people with dementia and their families, including communities and professionals
  - Professionals and others who understand and are able to support me and my family, and refer on for support which meets my needs
  - Professionals who try to understand our perspectives
  - Family doctors who provide regular appointments (with the same doctor) and assess our needs as individuals and as a family
  - An Admiral Nurse
  - Opportunities to address our own needs to remain well and to care for ourselves
  - Opportunities to meet with others who live with dementia and their families, together with my relative and separately to meet my own needs at times of day that are supportive of me
  - Support for children and young people that helps them cope emotionally and provides them with age appropriate information and helps me to help them
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## **Increasing need for care**

### ***Concerns and experiences***

As the needs of the younger person with dementia increased, the need for care became a particular challenge for many of the families involved in the consultation process. What was particularly evident from participants' feedback was that when the services they received were effective, this was as a result of a co-ordinated approach from professionals/ services involved (between social care, health care, primary care and voluntary/ independent services) where communication was frequent and knowledge about the person and family was transferred appropriately and seamlessly. Core themes arose from these discussions which are presented below.

### ***Time to make decisions***

When younger people with dementia living at home developed increasing needs for care and support, this created many challenges for the family. Participants described this time as particularly stressful, and for those family members in caring roles who were working, the point at which they had to make decisions about whether to continue to work or not, with the resulting implications this had for a range of issues including financial security. Some family members described difficulties with inflexibility from their employers, although others had managed to negotiate changes in working patterns. Among the difficult decisions raised by families including younger people with dementia, was the challenge of managing the implications of having care and support in your own home including the impact it might have on family life. Furthermore, while time apart continued to be expressed as an important need for many, family members also reflected upon the difficulties associated with ensuring that the younger person with dementia was happy and safe when such support was organised. Families often described losing friendships and networks of support, thus loneliness at these times made their situation more difficult.

### ***What is available and how do I access it?***

As highlighted earlier, many families including younger people with dementia highlighted that they often did not know what support was available and how to access it at the right time. This became a significant challenge when care needs increased, and some participants described an on-going difficulty in finding out what support was available from many of the services they had contact with, including knowledge about what they were entitled to and where to go for help. Furthermore, many expressed frustration at the lack of information which could assist them to plan for possible care needs in advance, to prevent crises occurring. Consequently, participants described feeling that they had been left to get on with it, and that they had to fight to get support. Indeed one family member said that

they had become someone they didn't recognise as a consequence of their constant battle to get the support they needed.

### *Achieving an assessment of needs*

Participants described negotiating the systems to achieve an assessment of needs as a complex undertaking. Communication from professionals and services involved in assessment and care provision was essential at this time, and some participants found that they received considerable support from different services including specialist mental health services, and Admiral Nursing. However others felt that they were not kept fully informed through the process of referral and assessment. Where assessment for social care needs was required, family members described difficulties with financial assessments for contributions to care. Some couples indicated that their shared assets were taken into account when assessing contributions, even though they were informed that this was not correct procedure. A few families felt that the level of financial contribution required was unacceptable given that they had contributed throughout their working lives.

For those who were assessed as self-funding, this further added to the difficulties already being experienced, as they felt that at this point services abandoned them. They felt that they had been given little or no knowledge and understanding of what was available and how to access the right sort of support. Others described difficulties when at assessment it was identified that they would have to transfer from one local authority to another due to living on the boundaries between authorities. These transfers frequently incurred considerable delays, resulting in hold-ups in receiving services. Such delays resulted for some in their situation becoming a crisis with all of the challenges that this created.

### *Finding appropriate care*

Many of the participants described difficulties in finding appropriate care that met the needs and abilities of younger people with dementia. This was particularly because the younger person with dementia often had different needs to that of older people experiencing dementia, including greater activity levels, better physical health, experiencing less common forms of dementia and importantly different life experiences and circumstances. These issues influenced attempts to find care at almost every point in people's journey with dementia.

### *Need for meaningful activity and occupation*

While the person with dementia had increased care needs, they also continued to need meaningful activity and occupation. Some felt that the available provision was often not tailored to support younger people, and that it did not meet individual needs. While some continued to find the support offered by Onside to be beneficial and meaningful, concern was expressed that this had to be curtailed or indeed come to an end because of the persons need for personal care, even though their need for activity continued. Provision of

flexible break vouchers and support from care agencies to deliver such support was experienced as highly variable in quality, with difficulties associated with continuity of carer, knowledge and skills to interact and ability to respond to the individual needs of the person with dementia. Thus some family members commented that they felt unable to leave the person with dementia and did not experience relief or respite for themselves. Day opportunities that meet the activity and occupation needs of younger people with dementia were also experienced as scarce in Worcestershire, with transport to get the younger person to the service being a further complicating factor.

#### *Respite Provision*

Finding local and specialist respite provision which was tailored to the needs of the younger person with dementia was also described by some as a particular problem. As will be explored under the heading of care home provision, while providers were saying they could offer support, the experience of the effectiveness of such support was variable and often levels of knowledge and understanding were felt to be limited. Respite in services which did not respond to or understand the needs of younger people and their families were often detrimental to the well-being of the person and their family and were then not used again.

#### *Care Home Provision*

Of particular concern to many family members was the lack of available local care home provision for younger people with dementia. Furthermore, some families felt that they were very much left alone to find the right sort of care home for their relative, and had very little knowledge of what they should look for. Some participants highlighted that while care homes may say that they take younger people with dementia, they found that the home would not necessarily have the experience or resources to meet the needs of the younger person with dementia. Some of the common issues included the lack of space and opportunities for meaningful activity and occupation for someone who was significantly more active than many of the residents in the care home. For some families this resulted in the person with dementia being moved on from one care home to another or to hospital, sometimes with very little notice. In one family member's experience, the younger person was moved 5 times in one year before a suitable care home was found. Some families had resorted to moving the person with dementia to a care home which was outside of Worcestershire, because that was the only care facility that could help and support the younger person with dementia and demonstrated the ability to do so. This clearly had implications for the frequency with which the person could be visited and the travel costs associated with this.

#### *Support for family members*

Some family members talked about the emotional journey that they underwent in coping with decisions to involve care agencies, place their relative in respite, use day care or to place someone in a care home. Families often had to achieve this negotiation of assessment

and help alongside many other competing demands in their lives, including for example work and other family member's needs.

Some families had access to Admiral Nurses and found this to be helpful. Additionally, others found that they received important support from Community Mental Health Professionals. However others felt unsupported and highlighted that much of the information and support they had was from other family carers rather than from professionals. At this critical point, family members in caring roles may have to make decisions about their own employment, and wanted practical and emotional support to help them to make the decisions that were right for them and their family. Families also highlighted the importance of support for themselves following their relative's admission to a care home. Some found that their needs were not acknowledged and that they felt that they were left alone to cope with the very difficult emotions experienced as a consequence of this decision. As before, the support needs of young people and children were raised, with families highlighting the need for specific support for them as individuals in their own right as well as support for families to help their children and young people cope.

### *The knowledge and skills associated with supporting younger people with dementia and their families*

One of the core issues people highlighted in the provision of services was that the level of knowledge and skill that professionals and carers had was particularly important in enabling care to be successful. Families highlighted that the knowledge and skills needed included understanding the different forms of dementia that were experienced by younger people, and the effects this had on their wellbeing. Additionally, it was thought to be necessary to understand the different experiences that younger people had, for example in their emotional wellbeing and physical activity needs. However, participants frequently highlighted concerns about a lack of this knowledge and skill, and emphasised the considerable difficulties this created. For example, they highlighted challenges for domiciliary care staff who did not understand the impact of less common forms of dementia and did not know how to approach or respond to the person with dementia, which on occasions resulted in the person rejecting their help and assistance. Furthermore, family members also highlighted that a lack of knowledge in professionals meant that they did not feel that they had been given adequate information or support in how to help and care for the younger person with dementia.

### *The need for continuity*

A theme throughout the consultations was the need for continuity with the professionals and services they received. This theme arose across all aspects of provision, from contact with their family doctor through to interventions from mental health and social care services.

Some of the participants indicated difficulties in getting regular reviews with their family doctor, and not being able to see the same doctor each time they visited. This was felt to be critical to understanding the younger person with dementia and meeting their needs as well as the needs of family members providing care. Participants also raised concerns about continuity with specialist mental health services, indicating that they felt that such services needed to be more accessible, particularly because families wanted to be able to plan ahead to prevent crises occurring. Some reported that they found specialist mental health services to be very helpful, but some also reported that when they did have services involved, appointments were often cancelled and no other support was forthcoming in these circumstances.

Continuity was also a concern within domiciliary care provision. The effectiveness of support from domiciliary care agencies was seen as being particularly reliant on the agency's ability to be flexible and to provide continuity in the workers who came to offer support. Where repeated changes of care staff occurred this was detrimental to the wellbeing of the person with dementia, and on occasions led their families to reject the support offered because it caused more stress and difficulties.

While personal budgets could be the solution to achieving continuity, some of the families who had been awarded personal budgets found the system to be unwieldy and complex, and that they had not been given enough information about how to manage it. Furthermore, participants did not always want the responsibility of being employers and experienced difficulties with accessing support from Penderels Trust [see glossary]. Ultimately this meant that for some, there was a delay in getting the care needed because of the challenges they experienced in managing the personal budget.

### *Specific Care Concerns*

A number of families raised specific care concerns related to physical health care needs at home or inpatient care and also about end of life care. These reflect many of the themes indicated above, including knowledge and understanding.

### *Continence Provision*

A few families identified difficulties in managing continence needs. Younger people with dementia are frequently much more active; consequently families found that the continence pads and nets were not helpful and were not dignified. Furthermore, they described that where Tena pads were offered as an alternative, they were rarely given enough to last a month, and families found that they had to purchase more pads to last until the next supply was delivered.



### *Managing medication*

A number of family members raised concerns about their ability to manage medication effectively and felt that they did not receive the education and information they required to do this well. One family member described this as feeling like you are caring with a gun held to your head, where there is no-one there in a crisis to help you to make a decision about whether to give medication or not.

### *Care in an Acute Hospital*

A few participants described experiences of care in an acute hospital. Some described positive experiences, including the appropriate provision of a single room to support wellbeing, and the opportunity for a family member to stay overnight. There were nevertheless concerns about the understanding of dementia, dementia in younger people and the care provision needed. In particular, some families indicated that the staff didn't appear to understand what the person with dementia could and could not do for themselves and mistakenly judged that the person could self-care in areas such as nutrition, and hydration. Family members also expressed concerns about the willingness of staff in some circumstances to engage with them, in order to learn how to care and support the younger person. Some participants had concerns that their interventions were not viewed as helpful or supportive, even when their presence and involvement enabled the person to remain settled. Those family members frequently felt they had to be present almost all of the time to be sure that their relative was well cared for. Some also expressed concern at the way in which they as family carers were treated during their relatives stay in the hospital.

Where a planned admission was needed, family members described the importance of communication with them about what the person with dementia would need in order to be prepared for the procedures, something which did not always happen.

### *Care in Specialist Inpatient Services for People with Dementia*

A few participants discussed perspectives concerning admission to mental health service provision. Some family members felt that the support offered was excellent, and that their perspectives were included and that they were supported too. They particularly emphasised that being involved and included in review meetings was very helpful. Where concerns were expressed these were commonly about the specialist knowledge that was required to support a younger person with dementia, which often related to the experience of less common forms of dementia and their impact upon wellbeing. Furthermore, some participants described difficulties with their relationships with staff, in that their perspectives were not always heard, and they didn't feel that the ward staff made active attempts to engage with them and understand their perspectives and experience in caring for their relatives.

### *Care at the end of life*

For some families, end of life care in a care home was experienced as particularly difficult. For one family, the service caring for their relative did not appear to have the experience or understanding of the needs of a younger person with dementia who was nearing the end of their life. This family emphasised the importance of having open and honest discussions between care home staff and themselves in order that difficulties are recognised and responded to quickly. In particular they emphasised the need for discussions about such issues so that hasty decisions at a time of crisis were avoided. There were also concerns raised about how families themselves were supported to manage the experience both during and following a person's death.

<b>Key Themes</b>	<b>Needs</b>	<b>Things that will help me/ us achieve these needs</b>
<b>We need to be heard and believed</b>	<ul style="list-style-type: none"><li>• That we are treated with respect and dignity</li><li>• That our perspectives (individual and shared) are listened to</li><li>• That we are treated as partners in care</li></ul>	<ul style="list-style-type: none"><li>• Staff understand and are able to implement person and family centred care</li><li>• Those who support us listen to our concerns and perspectives and don't make assumptions about us</li><li>• Those who support us seek to understand our history and the journey we have undergone before and how this has influenced our current situation</li><li>• Our perspectives are sought and we are included in decisions about care</li></ul>
<b>Knowledge and skills of professionals and carers concerning young onset dementia</b>	<ul style="list-style-type: none"><li>• Professionals, services and carers understand about young onset dementia and how it impacts upon our lives</li><li>• Professionals and services are able to help us to understand the experience of dementia and how we might manage the challenges associated with young onset dementia</li></ul>	<ul style="list-style-type: none"><li>• The professionals who support younger people with dementia and their families have specific training concerning our needs</li><li>• That care providers implement education and skills development for their staff in working with younger people with dementia</li><li>• Where transfer of care needs to occur, the staff taking over care are trained and supported to understand and respond to our needs</li><li>• That employers recognise that working with younger people with dementia is challenging and that staff need appropriate support and supervision to do this effectively</li></ul>

Key Themes	Needs	Things that will help me/ us achieve these needs
<p><b>A timely assessment of need</b></p>	<ul style="list-style-type: none"> <li>• To know how to get an assessment of need</li> <li>• That the process of assessment is understandable</li> <li>• That all of my needs are assessed as appropriate</li> <li>• That we are kept informed about the progress of assessment and how long it will take</li> <li>• That we understand the outcomes of assessment</li> <li>• That our financial circumstances are assessed appropriately</li> </ul>	<ul style="list-style-type: none"> <li>• A single point of contact to link with, who knows our situation and is able to help us to access an assessment in a timely fashion</li> <li>• Assessment occurs when we need it, and is proactive in considering the needs we have and how these might be met</li> <li>• Information about services provided in a brief form which shows us where to go to for what and what is available</li> <li>• We are given information about the process of assessment including timescales and procedures</li> <li>• We are provided with a copy of the assessment</li> <li>• The rules concerning financial assessment are clarified and we are given information about this</li> </ul>

<p><b>That we have choice</b></p>	<ul style="list-style-type: none"> <li>• We are given appropriate information about the services that are available</li> <li>• That I am involved in decision making where this is possible</li> <li>• I/ we are able to make informed choices about the services that we receive</li> </ul>	<ul style="list-style-type: none"> <li>• We have access to information that is kept up-to-date and that tells us what services are available, including those provided specifically for younger people with dementia and their families</li> <li>• The names and contact details of professionals involved in our care are given to us along with an explanation of what each professional does</li> <li>• We are involved in discussions about the services that we need and decisions are reached with us</li> <li>• Advocacy to help us to represent our needs when this is appropriate</li> </ul>
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**Key Themes****Needs****Things that will help me/ us achieve these needs****Advance planning**

- That we are able to plan for the future
- That we have emergency plans

- Professionals are open and willing to discuss the future and possible changes when I/we need this, so that I/we can have discussions about the future and our potential needs
- Discussion with professionals that helps us to plan for possible changes to prevent them becoming emergencies where possible
- Information about our emergency plans to be held by us and others
- 24 hour helpline

**Knowledge and skills to support us in coping with dementia**

- That we have information and knowledge to assist us to manage the impact of dementia

- That we are provided with information and training courses as appropriate to help us to manage the challenges associated with young onset dementia
- Information is tailored to our needs
- Information and advice about medication
- Information to help us to select the right care facilities
- Information about what care facilities provide, e.g. what Nursing Homes and Residential Care Homes provide
- Information about Continuing Health Care Funding and what this means

Key Themes	Needs	Things that will help me/ us achieve these needs
<p><b>Care provision that is appropriate to the needs of younger people with dementia and their families</b></p>	<ul style="list-style-type: none"> <li>• That I have meaningful activity and occupation that is responsive to my individual needs</li> <li>• That my family have the opportunity to have time for themselves as appropriate to their needs in the knowledge that my needs are being responded to</li> <li>• Where I need respite/ care home provision, that this is responsive to my needs and provided locally so that my family can visit regularly and be involved in my life</li> </ul>	<ul style="list-style-type: none"> <li>• Continuation of activity and occupation support when my need for personal care increases, so that I can continue to have fun and enjoy life, but provided by people who understand my needs</li> <li>• Day care that provide me with need appropriate activity and occupation, that support me to remain safe and allow my family to meet their needs for independent time</li> <li>• To be able to use flexible break vouchers to purchase day care where this provides activity and occupation as well as meeting personal care needs</li> <li>• Assistive technology to assist in maintaining independence and promoting safety</li> <li>• Professionals who understand personal budgets and can help us to manage the process effectively so that we can implement support that is tailored to our needs,</li> <li>• Professionals who can help us to make decisions about and access the right support when we are self- funding</li> <li>• Gradual introduction of domiciliary carers for personal care needs so the person can become familiar with them</li> <li>• The same carers involved so that the person with dementia accepts and becomes comfortable with them</li> <li>• For some people, a middle ground between personal budgets and local authority managed care is</li> </ul>

- desired
- Local provision of respite care that understands and is able to support younger people with dementia, that is need appropriate, for example providing activity and occupation and has enough space for activity and quiet space
- Local Nursing and Residential home provision for younger people, that is geared towards our needs
- I have a Family doctor who is linked to the care home

Key Themes	Needs	Things that will help me/ us achieve these needs
<p><b>My physical/ personal care needs are met</b></p>	<ul style="list-style-type: none"> <li>• My need for personal care is met with respect for me as an individual</li> <li>• My physical health needs are recognised and responded to appropriately</li> </ul>	<ul style="list-style-type: none"> <li>• The people who provide personal care understand me as a person and are able to support me to retain my dignity and privacy</li> <li>• I have access to a specialist dentist who can understand me and support my needs</li> <li>• I have regular contact with my family doctor and other health professionals as appropriate to ensure that my physical health care needs are recognised and responded to</li> <li>• I have access to specialist help where this is necessary, for example to help me with swallowing dietary needs and communication</li> <li>• When I need admission to hospital, that information about my care needs and routines are listened to and used to care for me</li> <li>• My family/ those who support me are able to be involved in my care while I am in hospital</li> <li>• Continence care is provided that</li> </ul>

Key Theme	Needs	Things that will help me/ us achieve these needs
<b>Continuity of provision</b>	<ul style="list-style-type: none"> <li>• That I know who the professionals and services are that are involved in my care</li> <li>• That I know who to contact to realise the support I need and discuss concerns</li> <li>• Where I need this, I have a familiar team of people supporting me in my everyday life, who know me and know how to support me</li> </ul>	<p>recognises my needs</p> <ul style="list-style-type: none"> <li>• A single point of contact</li> <li>• A description of the roles of the different professionals involved</li> <li>• Being aware that too many people involved can be difficult for the family to cope with</li> <li>• That information about my needs and who I am as a person is used by staff involved in my care, to understand me and support me effectively</li> <li>• That when I am transferred from one service/ professional/ carer to another, those involved in my care hand over and ensure that the new service/ professional/ carer is fully prepared to meet my needs</li> </ul>
<b>Coping with the impact of dementia on our lives</b>	<ul style="list-style-type: none"> <li>• I and my family have support when we need it to cope with the emotional, social and practical impact of dementia upon our lives</li> </ul>	<ul style="list-style-type: none"> <li>• Support from professionals that helps us to address as individuals and as a family the emotional experience of living with dementia and find ways of coping with the challenges we face, e.g. helping to manage the relationship between grandparents and grandchildren, coping with the impact upon our relationship, coping with the relationships we have with others</li> <li>• Not expecting children and young people to get involved in delivering personal care</li> <li>• An Admiral Nurse</li> <li>• Opportunities to meet with others in a similar position to share experiences and coping strategies in a location that is accessible</li> <li>• Buddies who understand our experiences, not all find Als Cafés helpful, but would value individual</li> </ul>



support

- Help to maintain our wellbeing as family members
- Recognition that we need to maintain activities and friendships as well as caring and supporting the person with dementia

## Conclusion

This consultation process has highlighted many concerns and needs. Younger people with dementia and their families frequently felt that these needs were not addressed appropriately. During the course of this consultation the views expressed highlighted that younger people with dementia required many things including;

- a need for a timely and well managed process of assessment and diagnosis and following this;
- The need for appropriate and tailored information, education and interventions that enabled them and their families to live with dementia.

This included recognising that people needed;

- Opportunities to maintain their identity and roles;
- A sense of security and peace;
- To be treated with respect, listened too and enabled to make and implement choices;
- Continuity with staff who are respectful and knowledgeable and provide relevant information;
- Knowledgeable staff who can support us effectively and;
- Care services that can provide support tailored to the needs of younger people with dementia.

Suggestions for how these needs could be met were discussed during these consultations. The results of these discussions will be brought together with the concerns expressed by services about what works and what doesn't work, and used to inform a planning meeting in April 2014. From this meeting priorities for action will be identified and a plan for implementation will follow.

Thank you to all of the people who contributed to this consultation.