



# *Living Well With Young Onset Dementia;*

**Working together with younger people with dementia and their families  
to make things better: A review**

**24<sup>th</sup> September 2015**

**Jenny La Fontaine, Young Onset Dementia Development Officer**

## Executive Summary

On the 24<sup>th</sup> of September 2015, a meeting was held to review the actions on priorities for support and services for young onset dementia, set in April 2014.

These priorities were:

- Raising awareness of young onset dementia in Worcestershire
- Increasing knowledge, skills and understanding in professionals and services
- Younger People and their families are assisted to address the implications of a diagnosis immediately following diagnosis
- Enabling people living with young onset dementia and their families to live well
- Providing care in a person's own home which is supportive of their wellbeing and their family/ significant others

Five working groups were established:

1. Education, Awareness and Training
2. Developing the care pathway
3. Information for younger people with dementia and their families: a website
4. Enabling people living with young onset dementia and their families to live well: a connection point
5. Developing care provision when an increased need for care is apparent.

A range of outcomes have been achieved, including;

- The inclusion of young onset dementia in the training of health and social care staff
- The development of a pilot questionnaire to support family doctors and their colleagues to identify younger people who need further assessment
- The development of a website, [www.youngonsetdementia-worcestershire.org.uk](http://www.youngonsetdementia-worcestershire.org.uk)
- The development of a new service, the Connection Point which runs monthly at County Hall
- The development of a set of draft standards to support care providers to work with people with young onset dementia

Seven people living with young onset dementia, 10 family members and 36 staff from a range of services working in Worcestershire attended this review. Attendees were asked to review actions undertaken and consider what more needed to be done.

A range of further actions were identified as needed which included;

1. Improving knowledge and skills of professionals working with people with young onset dementia and their families, including Family Doctors
2. Addressing the pathway into assessment and diagnosis, and the workload implications
3. Work with family doctors to ensure that timely and regular reviews are undertaken and where possible, crises are prevented.
4. Having YOD champions across all services
5. Ensuring that the website is tailored and accessible to people living with young onset dementia and their families, including making it available in other formats for those who do not access the internet
6. Building upon the successes of the Connection Point to make it more accessible and meaningful to those attending
7. Improving specialist care provision, including education for personal assistants, specialist provision of respite and a kitemark standard for providers of services for people with young onset dementia.

In addition to these suggested actions, it was also believed to be important to ensure that:

- The tender for the one to one service went ahead as planned
- Support for families, including children was considered more fully
- Support for relationships was considered
- Improvements in knowledge and skills occurred
- Improving care provision for people with young onset dementia and their families

Documentation of the discussions from the working group is included at the end of this report and is also available on the website. These discussions will be taken to the working groups and Young Onset Dementia Steering group for further consideration. Thank you to all who enabled the work to happen, and to those who attended and contributed to the meeting to make it a success.

## Introduction

This report provides a summary of the review meeting held on the 24<sup>th</sup> of September 2015. The purpose of the meeting was to review the actions undertaken over the past 18 months on the priorities set at the launch event in April 2014. These priorities were:

1. Raise Awareness of Young Onset Dementia within Worcestershire
2. Increase knowledge, skills and understanding in all professionals and services
3. Younger People and their families are assisted to address the implications of a diagnosis of dementia, immediately following diagnosis
4. Enabling people living with young onset dementia to live well
5. Enabling families of people living with young onset dementia to live well
6. Providing care in a person's own home which is supportive of their wellbeing and their family/ significant others

A further goal of this meeting was to consider what was needed to continue the work and to identify whether there are other priorities that we should focus on.

There were 54 attendees at this meeting including:

- 7 Younger People living with dementia
- 10 Family members of people living with young onset dementia

36 people representing services in Worcestershire including:

- Age UK
- Alzheimer's Society
- Association for Dementia Studies at the University of Worcester
- Hereford and Worcester Fire and Rescue, Vulnerable People Project
- Home Instead Senior Care
- Integrated Commissioning, Worcestershire County Council
- Older Adult Mental Health Services at Worcestershire Health and Care Trust, including the Early Intervention Dementia Service and Community Mental Health Services for Older People,
- Onside Independent Advocacy

- Stanfield Nursing Home
- Worcestershire Health and Care Trust including representation from Senior Management, Speech and Language Therapy, Patient Experience Department and Special Care Dentistry Services

Also 1 person attended who represented the Alzheimer's Society at a national level for young onset dementia.

The meeting began with an introduction from Sue Harris, Business Development Lead, Worcestershire Health and Care NHS Trust. This was followed by a presentation from Jane Twigg, who lives with young onset dementia. Jane described vividly and powerfully her experience of living with dementia which served to reinforce why we are doing this work. Jenny La Fontaine then delivered a presentation on the work that has been undertaken to address the priorities (this covered the information sent out before the meeting). Finally, members of our Dementia Voices Worcestershire group spoke about their involvement in our work together, and what they felt it had achieved. Kay, Steve and Roy presented a moving and inspiring account of their work and the motivations for being involved in the group.

## **Outcomes of the Meeting**

During the presentation, Jenny outlined the work that had been undertaken by many of those present. Five working groups were established after April 2014, to address the priorities set at that meeting. These groups were;

- 1) Improving public awareness of young onset dementia and increasing knowledge and skills in professionals and service providers.
- 2) Developing the care pathway to ensure that people with young onset dementia and their families have access to timely diagnosis and support following diagnosis
- 3) Providing information for people living with young onset dementia and their family members
- 4) Enabling people living with dementia and their families to access support following diagnosis and identify opportunities to support their health and wellbeing, A Connection Point
- 5) Addressing the need for the development of care providers that can support people living with young onset dementia and their family members as their need for care increases

A copy of the document which provides a summary of the work achieved since the review event can be found in appendix A (accessible summary) and appendix B (full report).

Those attending were then asked to divide into 5 groups, to consider the following questions:

1. What are your thoughts on what we have done so far?
2. What more do we need to do?
3. Are there other priorities that you think we should be working on?

The following key points were identified in these discussions.

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### **Education, Training and Awareness**

#### **What are your thoughts on what we have achieved so far and what more do we need to do?**

- The special interest group is positive and useful
- Need to work more closely with the media to improve their representation of young onset dementia (Local TV, Radio and News)
- More education for family doctors needed
- Increase amount of initial and on-going education on young onset dementia for professionals
- Improve opportunities to work together and develop knowledge and understanding through this

#### **What other priorities should we be working on?**

- Increasing awareness and understanding within hospitals and other organisations
  - Increased level of support for individuals
  - Involving people with young onset dementia in research
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### **The Care Pathway**

#### **What are your thoughts on what we have achieved so far?**

- Really positive that it is recognised that the whole family need to be involved
  - Positive steps to link with GP's through the pilot questionnaire
  - Encouragement for GP's to refer straight to EIDS working well
  - Having YOD champions who can raise awareness of young onset dementia within and external to the trust
  - Engaging with neurologists is working well
  - Information and support given is better
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### **What more do we need to do?**

- Address workload pressures that impact upon ability to provide support needed e.g. Early Intervention, Older Adult CMHT's and Dementia Advice Service
- Ensure that people are referred to the right service at the right time
- Work with GP practices to share good practice, encourage reviews and facilitate prevention of crisis
- Address the gap between EIDS and other services
- 'Finding' those people who are missing, e.g. diagnosed by private services or out of county,
- YOD champions across all services
- Should all younger people with suspected dementia go through EIDS?

### **What other priorities should we be working on?**

- Specialist care provision for respite and when care needs increase

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### **Information Provision for younger people and their families**

#### **What are your thoughts on what we have achieved so far?**

- A lot of information is available
- Positive work so far but recognition that a lot more needs to be done to make it fit for purpose

#### **What more do we need to do?**

- More personalised information to meet individual need is required
- Written information is not enough, there is a need for personal contact, to help understand and absorb information
- Making information accessible to people with different needs (e.g. font and size, colour, listen or watch)
- Provide information and links for other organisations (e.g. fire safety)
- 'Test' the website with a group of people who might access it
- Exploring the means through which people can be made aware of the website existence, e.g. your life your choice county council website



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- Use of social media and apps
  - Finding a partner agency to sustain the website into the future and exploring funding sources
  - Maintaining the focus on young onset dementia and finding ways of engaging repeat visits to the site
  - Forums or blogs

#### **What other priorities should we be working on?**

- Supporting relationships and the changing nature of relationships, and engaging other organisations in this process
- Supporting children and young people, awareness raising, education and support
- Information and support for people with less common forms of dementia

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#### **Supporting younger people with dementia and their families to live well, Connection Point**

##### **What are your thoughts on what we have achieved so far?**

- Venue easy to find and parking is ok
- Refreshments are good

##### **What more do we need to do?**

- Some speakers talk too fast, need to provide a short overview and focus on one topic at a time, so provide speakers with a briefing sheet to enable them to present in a dementia friendly way
- Work on ensuring the meeting can happen downstairs in County Hall
- Involvement of Social Care in planning and delivery
- New look invitation needed
- Add connection point update to the newsletter
- Involvement of people with dementia in steering group
- Reviewing who attends, gaining feedback when people stop coming

### **What other priorities should we be working on?**

- Transport arrangements for people wishing to attend who can't drive
- Other accessible means of being part of the connection point, e.g. live streaming, social media
- Further suggestions on themes for future meetings
- An awareness raising event to promote this and other young onset services, to promote the 'pathway'

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### **Improving care provision as needs increase**

#### **What are your thoughts on what we have achieved so far?**

- The standards were reviewed and approved by the group, felt to address the difficulties that have been experienced

#### **What more do we need to do?**

- To remember that the carers need support too, care provision has to be right for the whole family
- The standards need to become part of the admission process
- The industry needs to accept and apply standards (provision of a 'kitemark' of quality for those achieving the standards?) and have a willingness to learn
- Publish standards to make them freely available to families to use, empower them to identify what is needed
- Ensure that families can positively influence care provided

### **What other priorities should we be working on?**

- Life skills training for family carers
- Need to consider where next for best practice and care provision

A fuller representation of these discussions is included in Appendix C.

## **Next Steps**

It was clear that overall; the groups felt that significant progress had been made since April 2014, in addressing the priorities. Nevertheless, a great deal more work is needed if these priorities are to be adequately addressed.

A draft version of this report was sent out to all of those who participated, or who expressed an interest in hearing about the outcomes. Feedback was requested by the 11<sup>th</sup> of October. The report was amended to reflect the feedback received. The final report will be taken to each of the working groups and the Young Onset Dementia steering group. These groups will be reviewing the feedback received with a view to identifying plans to move forward with the work of that group.

## **Thanks**

**Thanks should go to a large number of people who helped to make it possible for the working groups to succeed and to make this meeting a success. These include:**

- Rachael Hodgetts, Anna Buckell, Hanneke Monks , Jo Scarle and Sue Davies
- Dawn Edmonds
- Dementia Voice Worcestershire, DEEP group and many other younger people living with dementia and their family members
- Carol Rowley and Jenny Dalloway, Integrated Commissioning Unit
- All Members of the 5 Working Groups
- The YOD Steering Group, Jan Austin and Nick Stephens
- The Alzheimer's Society and Age UK Dementia Advice Service
- The Early Intervention Dementia Service
- The Young Onset Dementia Champions and others in WHACT

## **Development of Services and Support for Younger People with Dementia and their Families**

### **Review of Action on Priorities set April 2014**

At the Planning Meeting held in April 2014, a number of priorities were identified;

1. Raise Awareness of Young Onset Dementia within Worcestershire
2. Increase knowledge, skills and understanding in all professionals and services
3. Younger People and their families are assisted to address the implications of a diagnosis of dementia, immediately following diagnosis
4. Enabling people living with young onset dementia to live well
5. Enabling families of people living with young onset dementia to live well
6. Providing care in a person's own home which is supportive of their wellbeing and their family/ significant others

### **Progress to Date August 2015:**

Five working groups were established to address these priorities. Achievements of each of these groups are highlighted below.

Working Group	Actions Achieved
1) Awareness raising, Education and Training	<ul style="list-style-type: none"><li>• Special Interest Group for staff working in Worcestershire</li><li>• Presentations by younger people living with dementia and family members to increase knowledge and understanding</li><li>• Professional training including young onset dementia</li><li>• Working with BBC Radio Hereford and Worcester</li></ul>

	<ul style="list-style-type: none"> <li>• Including young onset dementia in awareness raising campaigns Alzheimer's Society</li> </ul>
2) Care Pathway	<ul style="list-style-type: none"> <li>• Developing a team of young onset dementia champions with specialist knowledge and skills who will support the teams they work with to enhance care and support to younger people living with dementia</li> <li>• Developing ways of supporting early and timely detection in family doctors</li> <li>• Developing relationships with Neurology services to support assessment and appropriate referral</li> </ul>
3) Information Provision	<ul style="list-style-type: none"> <li>• Development of a website for younger people with dementia and their families in Worcestershire, which will include the perspectives of people living with young onset dementia</li> </ul>
4) Connection Point	<ul style="list-style-type: none"> <li>• Development of the pilot service which <ul style="list-style-type: none"> <li>○ provides support, education and information and;</li> <li>○ knowing who to contact when help is needed</li> </ul> </li> <li>• Supported by Alzheimer's Society, Age UK, Worcestershire Health and Care Trust and others</li> <li>• Commenced in June 2015, provided monthly</li> <li>• To be organised by the Alzheimer's Society from Sept 1<sup>st</sup> 2015</li> <li>• Positive feedback</li> <li>• Evaluation end March 2016,</li> </ul>
5) Care Provision	<ul style="list-style-type: none"> <li>• Development of standards for services for younger people with dementia and their families</li> <li>• Developed a training programme</li> <li>• Development of ways of auditing organisations that provide care</li> </ul>

We have also established **Dementia Voice Worcestershire (DEEP) Group** to include the perspectives of younger people with dementia and family members in our work.

Dementia voice is an activist group of younger people with dementia and family members who seek to bring about change in Worcestershire in the services and support that is offered to younger people with dementia and their families. The group has been involved in;

- Creating a more positive image of people living with young onset dementia through presentations, the development of a website and through our individual contacts with others
- Influencing the development of services for younger people
- Fighting bureaucracy
- Representing the views of people who are less able to express their own perspectives.

Finally, work has also occurred to develop the existing one to one service, a priority for the coming year will be to ensure that an organisation is identified to deliver this service according to the new requirements.

## Appendix B

### Development of Services and Support for Younger People with Dementia and their Families

#### Review of Action on Priorities set April 2014

At the Planning Meeting held in April 2014, a number of priorities were identified for action. These were;

Key Area	What will it address
Raise Awareness of Young Onset Dementia within Worcestershire (Priority 1)	Increase awareness of young onset dementia in the wider community, including workplace, education, schools, business and professionals
Increase knowledge, skills and understanding in all professionals and services (Priority 2)	Identify and deliver training targeted at different occupational groups, that builds upon existing knowledge base
Younger People and their families are assisted to address the implications of a diagnosis of dementia, immediately following diagnosis (Priority 3)	Ensuring that younger people with dementia and their families receive tailored, appropriate information, education, psychological and practical support following diagnosis
Enabling people living with young onset dementia to live well (Priority 4)	Supporting the delivery of person centred care, which recognises the psychological, spiritual, social and physical needs of younger people with dementia within the community of Worcestershire
Enabling families of people living with young onset dementia to live well (Priority 5)	Supporting the development of family centred care, which recognises the psychological, spiritual, social and physical needs of families within the community of Worcestershire
Providing care in a person's own home which is supportive of their wellbeing and their family/ significant others (Priority 6)	Supporting the delivery of care in a person's own home, by people who are knowledgeable, and able to deliver continuity and person centred support as well as supporting family members through information, education and care for their needs

In order to address these six priorities, five working groups were established with outcomes identified as follows;

### **Group 1; Awareness Raising, Education and Training**

1. To increase awareness among the general public that;
  - a. Dementia occurs at a younger age
  - b. It is possible to live well with dementia
  - c. The forms of help and assistance that people may need and how individuals and organisations may support this
2. To increase knowledge, skills and understanding in professionals and services concerning the experience of living with young onset dementia and how to support and assist younger people and their families to live well through

### **Group 2: Care Pathway for Young Onset Dementia**

1. To identify, design and implement additions to the existing care pathway within Worcestershire Health and Care NHS trust which facilitates appropriate and evidence based care for people with dementia and their families from the beginning of their experience of cognitive symptoms, through diagnosis, increased need for care and end of life care. These additions will specifically address those who are deemed to have complex needs. Complexity is viewed as those who are experiencing;
  - a) A younger age of onset which involves specific and frequently multiple psychosocial implications such as family obligations, employment and financial circumstances and/or
  - b) Less common forms of dementia and/ or
  - c) Complex family circumstances which may include the presence of dependent children/ young people and challenges in coping with the changes occurring

### **Group 3: Information for people living with Young Onset Dementia and their families**

1. To provide a website for Young Onset Dementia in Worcestershire, which will be accessible and available as a resource for;
  - a) People living with young onset dementia,



- b) Family members and significant others who live with and/or care for a person with young onset dementia
- c) People who wish to know more about young onset dementia
- d) Staff who work with people with young onset dementia and their families

**Group 4: The provision of support which enables younger people with dementia and their families to live well**

1. Providing a Connection Point Service for Younger People with Dementia and his/her Family Members/ Significant Others. This service will provide:
  - a) A regular and on-going point of contact in order that the person and their family can access timely advice, education, support and information as appropriate to their needs
  - b) The opportunity to build relationships with professionals and services in order that they know who to access to meet their needs and can experience a degree of continuity of support through the time that they live with dementia
  - c) Opportunities through formal and informal education and information sessions to address the range of issues that may influence their health and wellbeing

**Group 5: Care Provision for younger people with dementia who have increased needs and their families**

The group will develop a set of standards and associated training and audit which will support Providers of Care Services in a person's own home and within a care setting to develop their service to provide care to younger people living with dementia and their families

**Progress to Date August 2015:**

Working Group	Actions Achieved
1) Awareness raising, Education and Training	<ul style="list-style-type: none"> <li>• Special Interest Group for staff working in Worcestershire on Young Onset Dementia (bi-monthly since July 2014) which has achieved regular and consistent attendance from a wide range of agencies including Age UK, Alzheimer's Society, CAB, Onside and the Health and Care Trust</li> </ul>

	<ul style="list-style-type: none"> <li>• Presentations by younger people living with dementia and family members to increase staff knowledge and understanding</li> <li>• Incorporation of Young Onset Dementia into higher education courses for professionals, including social work, nursing, and primary care (GP's etc.)</li> <li>• Working alongside the media to improve perceptions of young onset dementia (interviews with BBC Radio Hereford and Worcester, Working on a Day in the Life of a younger person with dementia)</li> <li>• Working alongside Alzheimer's Society to incorporate young onset dementia into their awareness raising sessions</li> <li>• The work of other groups also contributes to these outcomes</li> </ul>
2) Care Pathway	<ul style="list-style-type: none"> <li>• Agreement from within Worcestershire Health and Care NHS Trust to develop specific additions to the care pathway in order to ensure younger people with dementia and their families are recognised and supported</li> <li>• Identification of Young Onset Dementia Champions from each team within Older Adult Mental Health Services to form a virtual team. The team have now formed and identified role and function</li> <li>• Have reviewed knowledge and understanding of young onset dementia in order to inform pathway development</li> <li>• Have made contact with other services to learn from them about care provision</li> <li>• Pilot underway to support early and timely detection in primary care</li> <li>• Meetings to develop relationships with Neurology services to support assessment and appropriate referral</li> </ul>
3) Information Provision	<p>Development of a website for younger people with dementia and their families in Worcestershire.</p> <ul style="list-style-type: none"> <li>• Reviewed existing websites to explore what is already available to avoid repetition</li> <li>• An actual website has been developed, but a work in progress!</li> </ul>

	<ul style="list-style-type: none"> <li>• Provide links to existing resources and websites</li> <li>• To provide information written by people living with young onset dementia and their families</li> </ul>
4) Connection Point	<p>Development of a pilot of a 'connection point' to provide continuity of support, education and information</p> <ul style="list-style-type: none"> <li>• Development of the model</li> <li>• Consultation with people living with young onset dementia and families</li> <li>• Identification of support to staff the service</li> <li>• Pilot of the connection point commenced in June 2015.</li> <li>• Multi-agency involvement</li> <li>• Alzheimer's Society to take on organisation from Sept 2015</li> <li>• Formal reporting on evaluation March 2016</li> <li>• Proposal to continue beyond March 2016</li> </ul>
5) Care Provision	<ul style="list-style-type: none"> <li>• Review of literature and existing service provision to identify models and perspectives on best practice</li> <li>• Development of an accessible set of standards informed by values about services for younger people with dementia and their families</li> <li>• Developed a training programme for young onset dementia for staff working in care homes and domiciliary care, currently exploring how this can be implemented</li> <li>• Development of audit process associated with standards underway</li> <li>• Identification of need to develop care home provision</li> </ul>

In addition, a significant piece of work has been undertaken to develop the specification for the existing one to one service provided by Onside, to reflect the needs and wishes of people living with young onset dementia in Worcestershire. A new service specification has been designed and although some delays have been experienced, it is anticipated that the procurement of a service in line with this specification will be a priority for the coming year.

We have also established **Dementia Voice Worcestershire (DEEP) Group** to include the perspectives of younger people with dementia and family members in our work.

Dementia Voice is an activist group of younger people with dementia and family members who seek to bring about change in Worcestershire in the services and support that is offered to younger people with dementia and their families. The group has been involved in;

- Creating a more positive image of people living with young onset dementia through presentations, the development of a website and through our individual contacts with others
- Influencing the development of services for younger people including the specification for the one to one service currently provided by Onside
- Fighting bureaucracy
- Representing the views of people who are less able to express their own perspectives

### **Next Steps**

Clearly, some of this work will need to continue and build upon the foundations we have laid over the past 18 months. This includes;

- The work of the young onset dementia champions and within this;
- The development of the care pathway within the Health and Care Trust;
- Improving awareness, knowledge and skills of young onset dementia and;
- The development of the Website.
- To appoint an organisation to deliver the one to one service for younger people with dementia

The Connection Point service is early in its pilot but has received very positive reviews so far. An evaluation report will be produced at the end of March 2016, and at this point discussions and decisions will be made concerning how the service should be delivered in the longer term.

Finally, the standards, training programme and audit process for care provision for younger people with dementia is being finalized and the process for implementation will need to be the next step in creating expertise within the care sector.

This meeting is an opportunity to review progress and hear the perspectives of people working with or living with young onset dementia on the work we are

doing. It will also be an opportunity to consider how we might progress into the future.

## **Thanks**

We would like to acknowledge the tremendous commitment of many people to the work that has been undertaken to find ways to develop the support offered to younger people with dementia and their families over the last 18 months.

These include:

- Members of Dementia Voice Worcestershire, DEEP group
- The YOD Steering Group
- Carol Rowley and Jenny Dalloway, Joint Commissioning Unit
- Members of the 5 Working Groups for Young Onset dementia,
- Dawn Edmonds
- The Alzheimer's Society and Age UK Dementia Advice Service
- Many individual younger people living with dementia and their family members
- The Early Intervention Dementia Service
- In particular Rachael Hodgetts, Anna Buckell, Hanneke Monks and Jo Scarle
- The Young Onset Dementia Champions.

## **Appendix C:**

### **Full Feedback from the group discussions 24.09.15**

#### **Group 1: Information, Education and Awareness**

- Work with the press and media needs to be on-going, we need to challenge their language use and support local media to raise awareness
- Educating GP's and exploring how we engage them
- Special Interest Group useful
- Need for more education and training for professionals, induction and on-going available, through trusts and other employers, not just a 10 minute session
- More opportunities for partnership working, allowing organisations to learn from each other in terms of roles
- Change use of language - pinpoint a media company to work with
- Professionals need to be better informed about YOD and less common variants. They need to be prepared to find information for individuals and explain and discuss it.
- More use of social media, twitter and facebook

#### **Other priorities**

- Hospitals and other organisations, improving awareness of YOD in those groups, it's not just about people over the age of 65/ 75
- Greater opportunities to involve those living with YOD in research
- Greater immediate support for individuals

#### **Group 2: Care Pathway**

##### **Positives;**

- It's really positive that it has been recognised that the whole family need to be involved
- Pilot with GPs is a positive move
- GP dementia leads being established
- Engaging with Neurology is also a positive move
- GP referring straight to EIDS works well
- YOD Champions raise issues in and around the trust
- Information that's given to people and support is so much better now

Difficulties that need addressing;

- Concern about workload issues;
  - EIDS service, referrals, work pressures
  - Age UK Dementia Advisors under pressure
  - Too few resources
  - OAMHT - Possible diagnosis currently referred to Adult team then back to OAMHT - difficult for people
- Gap between GPs and EIDs and OAMHT - regular reviews to help prevent crisis
- Clarifying who is best to support someone - which team? This needs to be sorted out
- Should every person with suspected YOD go through EIDS?
- Concern about the number of people 'missing' from our services
- Moving on - the gap when discharged from EIDS is difficult
- More work with GP practices to share good practice across all GP services
- Other services - podiatry, dentists
- Right team at the right time
- Still inconsistent
- Those who are diagnosed privately may not be provided with access to support, how can we help private practitioners to refer on
- Having immediate GP access to a named GP, still difficult to get appointments when needed and to prevent crisis despite dementia register

Other priorities:

- Specialist care provision, respite and for later on needed

### **Group 3: Information**

- More personalised information needed, it's not enough to be given written information and it can be daunting to receive so much info
- Info to be more accessible, face to face support is important
- Need more information on specific and less common forms of dementia

Website:

- Need to be clear about what's different about this particular website, how does this fit with other websites. It's important that focus on young onset dementia is kept
- Ownership - who is going to maintain responsibility for the website, how can we ensure the website continues? Support and funding - Professional partner e.g. Worcester University?
- Use of advertising? Which might help with funding? Would employers be interested in being involved? Sponsor website?
- Need to maintain interest in the website, regular updates/ news items (put newsletter on the front page) also have a number counter to see how many people are accessing it
- Accessing the website;
  - Transfer of content to the Trust website, ensuring that people can access that website, have a link on the existing website page that people can go straight to
  - A link to this website on the County Council Your life your choice website
  - Carers Newsletter
  - Making it available at each Connection Point meeting
  - Asking people to bring along their own iPad/ Laptop to access it at the Connection Point
- Accessibility issues for the website;
  - Use of different languages on website
  - Not everyone uses a computer
  - Technical issues, maintenance - colour of background and text, Language barriers
  - An 'app' that can be downloaded onto smartphones?
- Content of the website;
  - regular updates, news stories, research
  - Links to dementia friendly communities,
  - Use of hyperlinks to enable people to move from one website to another without losing their place
  - Including links to the fire service, vulnerable persons and possibility of capturing anonymous data where 'near misses' have occurred



- Helping carers to work for as long as possible, addressing solutions to risks
- Where to go to get more help needs to be a continuous theme
- There is a need to consider how much we address the needs of people living with YOD and their families together and separately
- Regular meeting of groups to test the usefulness of the website and its content
- A 10 point list, what works and doesn't work
- Link people to talking point
- Possible forum/ closed groups for discussions
- How to help people to remain in work or take up other opportunities

Other priorities to be addressed:

- Emotional impact of dementia, recognising difficulties - engaging with counselling organisations who have not traditionally worked with people with dementia
- Relationships between children and grandchildren, how the impact is experienced and how we can support their increased awareness and understanding
- Less common forms of dementia need better understanding and interventions

#### **Group 4: Connection Point**

- Speaker use of jargon, some speaking too quickly or too much information. We need to provide them with a briefing sheet so they understand what to talk about. Speaker to think about issues they may have come across and use examples to explain the topic they are addressing, then invite open questions
- Venue - mixed views - issue with upper gallery area, ground floor is a better location, access to toilets etc. Need to sort out whether we can use the ground floor on a regular basis
- Issues around transport issues to venue need to be resolved
- Person living with YOD to join steering groups/working groups - invite participant from Connection Point to these meetings to give feedback
- Revisit list of attendees - contact via phone - personal connection, particularly when people attend once and then don't come again.

- Invitation needs to be simplified and made more inviting
- Promote Connection Point - 150 on database but more need to know about it. Promote on Website, possible Facebook page for Connection Point - Also would be helpful to put information about the connection point in the newsletter
- Suggestion that we make it accessible to people who cannot attend, by Filming speakers or Skype stream to website.

### **Future sessions**

- Fire safety and keeping safe,
- Input from social care, carers assessments, form filling, new rules on social care, e.g. respite, personal budgets, understanding who does what.
- Speakers from the Alzheimer's Society, Age UK Dementia Advice Service and Admiral Nurses
- Use of images

### **Group 5: Care Provision**

- Remember that we are the carers, care provision needs to make it right for the whole family
- There are common themes and standards in domiciliary and residential care homes
- Standards need to migrate into the admission process, to make it possible for an appropriate choice to be made
- The care industry needs to accept and always apply the standards, perhaps providing a 'kitemark' for organisations conforming to the standards
- There must be a willingness to learn on the part of the organisations delivering care
- A need to consider how to attract the right people to become carers
- Publish standards

### **Other priorities**

- There needs to be life-skills training for family members who have to take on roles they have not previously undertaken
- A need to consider where next for best practice in care provision