Supporting Younger People with Dementia and their Families
Planning Meeting, 9th April 2014
Final Report

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Introduction

This report summarises the results of a planning meeting held on the 9th of April 2014, which was the culmination of the consultation work carried out with younger people living with dementia, their families and the professionals and agencies that work with them in Worcestershire. The purpose of the event was;

- To present the results of the consultations and the 'roadmap' that had been developed from this
- To have discussions concerning what support and services might look like for younger people living with dementia and their families at different points in their journey
- To identify the key priorities for action over the next two years

One hundred and fourteen people came together at the meeting. These included;

- 13 younger people who live with dementia
- 23 family members who are or were previously supporting a person living with young onset dementia;

And representation from;

- ACT
- Age UK
- Alzheimer's Society
- Association for Dementia Studies at the University of Worcester
- Aspire Active Days
- Friends of the Elderly
- Hereford and Worcester Fire and Rescue, Vulnerable People Project
- Heritage Manor
- Home Instead Home Care
- Joint Commissioning Unit, Worcestershire
- Older Adult Mental Health Services at Worcestershire Health and Care Trust, including the Admiral Nursing, Early Intervention Dementia Service and Community Mental Health Services,
- Onside Independent Advocacy
- Sanctuary Care
- Stanfield Nursing Home
- St Richards Hospice
- Thursfields Solicitors
- Well Connected
- Worcestershire Acute Hospitals
- Worcestershire Association of Carers

- Worcestershire County Council Carers Unit
- Worcestershire Health and Care Trust including representation from Senior Management, Speech and Language Therapy, Social Work
- University of Worcester Pre-registration Nursing

After hearing from younger people with dementia and their family members about their experiences of living with young onset dementia, followed by a presentation on the outcomes of the consultations with younger people with dementia, their families and staff who work with them. The roadmap was also presented, highlighting many areas that need further development. We then heard from a service in Berkshire, who has developed innovative ways of supporting younger people with dementia in recent years Following this, discussion took place in 11 separate groups, addressing the following issues;

1) Improving public awareness of young onset dementia and increasing knowledge and skills in professionals and service providers.
2) Assisting primary care to recognise and respond to the needs of younger people with suspected difficulties and refer on and following diagnosis, supporting primary care to enable younger people with dementia and their families to cope well following diagnosis
3) Ensuring that a younger person receives a knowledgeable, coordinated, timely and supportive assessment of need and difficulties and following this, a sensitively shared and accurate diagnosis
4) Ensuring that the person with a diagnosis and their family are supported immediately following diagnosis, psychologically and practically to address the implications of this diagnosis for their lives
5) Enabling people living with young onset dementia to have purpose in their lives
6) Enabling people living with young onset dementia to live well, (considering emotional, physical, spiritual and social needs)
7) Enabling the families and significant others of people living with young onset dementia to live well (considering emotional, physical, spiritual and social needs)
8) Providing care in a person's own home which is supportive of their wellbeing and their family/ significant others
9) Providing care in a care home that is supportive of the wellbeing of the younger person with dementia and their family/ significant others
10) Providing care in a general hospital that is supportive of the wellbeing of the younger person with dementia and their family/ significant others
11) Enabling younger people with dementia and their families to make advance plans and ensuring that end of life care is supportive of the needs of younger people with dementia and their families

Each working group was asked to consider the following 3 questions in relation to this issue;

1) What might this look like so that it works well?
2) Who would need to be involved to make it happen?
3) What would be needed to make it happen?

Following feedback, those present were asked to identify the priorities for action over the next few years. A brief summary of the results of the priority setting exercise are presented first on pages 5 to 6, followed by an outline of next steps.

In Appendix A, each of the topics that were discussed are presented in more detail, outlining what was covered in the discussions and noted down on flip charts and in feedback, in numerical order. The priority areas, as identified on the 9th of April are highlighted in bold. Other issues of significance highlighted in the priority setting exercise are also highlighted in bold. Appendix B identifies the list of professional attendees at the planning event.

We would like to thank all of those people who attended and/ or contributed to the success of the planning meeting. Particular thanks are due to the younger people with dementia and their families who were prepared to share their stories, to the Young Onset Dementia Steering Group, to those who chaired the working groups and to Professor Dawn Brooker and staff at the Association for Dementia Studies.

Priority Areas

Key Area	What will it address	How
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	• Build Young Onset Dementia into the next national campaign and events occurring locally • Use social and free media • University skills bus • Use models from other health campaigns • Dementia friendly communities • Intergenerational education in schools
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	• Inclusion of YOD in existing course provision for professionals and carers in training • Training for Primary Care Practitioners • Use of experts by experience in delivering training and education • Identification of priority areas for training provision e.g. home carers, care home staff and plan for delivery and implementation
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	• Co-ordinated approach to assessment, diagnosis and post-diagnostic support • Continuity of support during assessment, diagnosis and post diagnostic intervention • Clear information, a pathway for people with dementia and their families • Interventions to adjust and adapt, to live well

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	• Multi-agency involvement in the development, delivery and accessibility of support which addresses areas including;
		  ○ Age and need appropriate activities, including engagement in volunteering and work where this is relevant
		  ○ Support to manage financial needs
		  ○ Continuity of relationships
		  ○ Transport to access services

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	• Training for those working with carers and people with dementia as in priority 2 • Education for families and carers • Better information and support to access services, including web based information • Support to manage financial needs • Admiral Nurses • Open referrals • Effective support for children including engaging with schools
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	• Knowledgeable home carers • Care agencies with specific understanding of the needs of people with young onset dementia • Normalised care which is holistic • Day opportunities • More community engagement, a community champion • Build on support networks of the family • Continuity of support

Next Steps

Evaluation of the planning event suggests that it was successful in bringing many people together to consider and discuss how we might move forward. Attendees particularly valued the opportunity to meet with each other and discuss their concerns in a meaningful and constructive way.

However, it was evident from feedback that the priority setting exercise did not give those attending enough time to consider their priorities. Furthermore, there were many people who were not able to attend the event but would have valued being involved. Therefore, the first of the next steps involves an extension to the priority setting exercise.

Step 1: Priority setting

Further consultation will take place concerning the priorities identified for action for the next few years. Those who wish to influence the priorities identified, should read appendix A, which contains the written feedback from the discussions in the working groups. Having read these, they are requested to complete the form that is enclosed with this report, identifying their top 3 priorities. Respondents will also be asked if they are interested in being part of any working groups addressing these priorities. Responses were returned by email or post on the 14th of May 2014.

Step 2: Confirmation of Priority areas and publication of the final report

Following receipt of the consultation regarding priorities, 6 priority areas have been confirmed. This report has been sent to all who attended the event and those who wish to be kept informed.

Step 3: Working groups

Working groups are to be set up to address each of these priority areas. Each working group will identify terms of reference and we welcome multi-agency and multi-disciplinary involvement as well as experts by experience. Working groups will report on progress through their chair person to the Young Onset Dementia Steering group which meets quarterly. The first two meetings of each working group will set the terms of reference and priorities for action, which will be reported to the steering group and the Dementia Care Planning Group meeting by September 2014.

Step 4: Review of progress

As indicated on the 9th of April, a date for review of progress will occur in May 2015. This meeting is likely to be for half a day and will;

1. Report on progress on each of the priorities
2. Review perspectives on progress and actions needed
3. Discuss priorities needed for the coming year

Appendix A

Group 1) Improving public awareness of young onset dementia and increasing knowledge and skills in professionals and service providers (Priority 1)

What might this look like?	Who would need to be involved?	What would be needed to make it happen?
National and local recognition of young onset dementia	• Professionals, organisations and service providers in all settings • Engage free media and **social media** • University Skills bus • Medical Charities and Famous Campaigners • **Schools Champions**	• Identify clear outcomes and objectives • Build on next national campaign • Work to challenge perceptions in practical ways, using existing services and events, • Use models from other health campaigns • Intergenerational education in schools
Increasing knowledge, understanding and skills In ALL professionals, in health, social care and other providers who come into contact with younger people and their families	• Universities and colleges • Training departments of all organisations • Experts by experience • Staff with specialist knowledge	• **Training in young onset dementia for all staff early in their training** • Identify professionals by group and make training relevant to each group, scenario/ case study based training • Increase knowledge of services so signposting can occur

Group 2) Assisting primary care to recognise and respond to the needs of younger people with suspected difficulties and refer on and following diagnosis, supporting primary care to enable younger people with dementia and their families to cope well following diagnosis

What might this look like?	Who would need to be involved?	What would be needed to make it happen?
Mandatory training for Primary Care Practitioners	• GP's and other primary health care practitioners	• Patient participation group • Information on services and pathways • Specialist GP's/ Practitioners • In house training
Improved communication between all parties and therefore timely recognition and response	• Primary Care practitioners, younger people with dementia or suspected symptoms and their families	• Address barriers to open communication • Address time constraints • Information to patients and families about what they can expect
Joint working between Primary and Specialist Services	• Primary Care and Specialist services	• Open Communication • Support/ area workers in surgeries • Continuity • Registration on QOF

Group 3) Ensuring that a younger person receives a knowledgeable, coordinated, timely and supportive assessment of need and difficulties and following this, a sensitively shared and accurate diagnosis

- Using the word dementia early on, not acceptable to avoid this
- Talk about dementia before the assessment starts, pre-assessment counselling
- **Choice, about having the assessment, who is present, when it happens, time to reflect on when to have it**
- Setting for sharing the diagnosis, formal but not too formal, calm and respectful
- Sensitivity of the process of sharing a diagnosis
- Stressing the positives, the value of knowing, next steps and engendering hope
- How we help people to make a timely choice, to minimise delays
- Need to work with colleagues in other services who deliver the diagnosis
- Making sure that families are aware of the need to be honest and open about what is happening, and the person who is experiencing symptoms as well
- **Continuity**

Group 4) Ensuring that the person with a diagnosis and their family are supported immediately following diagnosis, psychologically and practically to address the implications of this diagnosis for their lives (Priority 3)

- **Continuity – A key worker forever!**
- **Help around benefits**
- **Simple and clear information about what is available at each stage**
- **Knowing where to go and who to ask**
- **Good communication and sharing of information between professionals**
- **Normality**
    - Support to live your own life
    - Can dip into services when needed and flexible to individual needs
- **On-going assessment /review/monitoring**
- Peer support, locally provided
- Time to adjust to the emotional impact
- Time to learn strategies to cope, together and separately
- Age appropriate activities and interests

Group 5) Enabling people living with young onset dementia to have purpose in their lives

What might this look like?	Who would need to be involved?	What would be needed to make it happen?

• Day service opportunities
• Support groups
• Feeling included in meaningful occupations
• Flexibility in what purpose means, should include;
  ○ Employment
  ○ **Voluntary work**
  ○ Activities
• **One to one and groups**
• Adapting activities to respond to need
• **Life story work**
	• **Supporters to assist with access**
	• **Someone to assist with transitions**
	• Co-ordinator to find opportunities
	• Transport services
	• **Alzheimer's Society/ AgeUK**
	• **Dementia Friendly Communities**
		• **Directory of resources for professionals, younger people and their families**
		• Age appropriate activities
		• Signposting
		• Organisations and professionals to work together
		• **Continuity**
		• **Flexibility to adapt to changing needs**

Group 6) Enabling people living with young onset dementia to live well, (considering emotional, physical, spiritual and social needs) (Priority 4)

Medication	• Education and training to understand how it works and what it does, better explanations
Financial Security	• More education, for DWP to adjust process to meet needs of younger people with dementia
Activities	• **Age appropriate and providing support tailored to need (group and one to one) addressing barriers to access and ensuring good communication**
Peer Support	• Tailored to individual need
Continuity	• Need to be able to build a trusting relationship and receive on-going care and support
Transport	• Enhance transport provision to enable people to access social places, education of transport providers required

Group 7) Enabling the families and significant others of people living with young onset dementia to live well (considering emotional, physical, spiritual and social needs) (Priority 5)

What might this look like?	Who would need to be involved?	What would be needed to make it happen?
An individually tailored approach to family needs, recognising psychological, social, spiritual and physical needs as individuals in their own right	○ Younger person with dementia and their family members ○ Skilled workers, Admiral Nurses ○ Paid Carers who are able to provide • Consistency • Right training • Meaningful activity • And are Person centred ○ **Speech therapist** ○ Primary care ○ GP ○ Commissioners ○ **DWP/Financial advisors** ○ Voluntary/independent sector e.g. Alzheimer's society	• **Staff training. GP Education.** • **Financial security** • Education of other agencies • **Better signposting** • Easy access to services • Improved websites and eLearning • Legal services involved early on • **Better education for carers which is** ○ **Face-to-face and flexible** ○ **Choice of how received** ○ **On size doesn't fit all** • **Psychological support** • Addressing everyday needs such as sleep, employment and exercise • Effective support for children including engaging with schools, to inform and educate • **Helpline with personal info available, know person** • **Open referrals** • **Admiral Nurses**

Group 8) Providing care in a person's own home which is supportive of their wellbeing and their family/ significant others(Priority 6)

What might this look like?	Who would need to be involved?	What would be needed to make it happen?
• Warm, safe, stimulated, sociable, person centred, providing respect and dignity of care which is normalised • Responsive to needs • Providing support and education for family carers and recognise changes in relationships • **Education for home carers** • YOD specific focus for care agencies CQC registered • Proactively assessed by provider to cover ALL aspects of care • Carers appropriate for person • **Continuity is vital** • Commissioners need to look at whole picture when procuring services	• More community/voluntary involvement to meet individual needs of a person and their family • Need a community champion • Information packs to build on own support network • **Key worker/enabler to get network up and running for an individual/family. Help equip carers with tools and skills to facilitate care**	• **Services need to be more cost accessible for clients and their families** • **Community groups/Day care** • Organised by like-minded people – volunteer groups • Address knowledge and safeguarding • Recruitment/training support • Better pay for carers • Office staff who organise carers need to understand what carers do • Longer visits for clients, financially affordable • Better training to cover YOD • **Domicillary care agencies with specialist YOD dementia trained staff**

Group 9) Providing care in a care home that is supportive of the wellbeing of the younger person with dementia and their family/ significant others

What might this look like?	Who would need to be involved?	What would be needed to make it happen?
• Staffing to enable people to take part in meaningful activities outside of the home • Separate wing, Small and intimate • Skilled staff/consistency • Meaningful activities for people and carers • Size/number of people compared with income of home/care provider	• Person with YOD • Significant partner/family/life associates • Caring professionals • Commissioners (service) •	• **a collaborative approach** • a realistic response to the financial implications of the cost of younger onset dementia • Raising awareness

Group 10) Providing care in a general hospital that is supportive of the wellbeing of the younger person with dementia and their family/ significant others

What might this look like?	Who would need to be involved and what would be needed to make it happen?

• Talk to patient and carers
• About me documents
  ○ Standardised formats
• **Increased staff awareness & understanding of young people with dementia and what this means**
  ○ Types, symptoms, capacity
• Planned admissions should have a plan of care
  ○ avoid repetitive questions
  ○ include contact list
• **Dementia Care Pathway**
  ○ Hospitals should look at existing systems including mandatory training
• **Better environments, 'dementia friendly'** including Signage, cues, colours etc.
	• Trusts sign up
	• **Local politician** and public support
	• Project team to include:
	  ○ Patient and carer
	  ○ MDT
	  ○ Facilities
	  ○ Corporate services
	  ○ Resources: human/finance/literature
	  ○ Partners

Group 11) Enabling younger people with dementia and their families to make advance plans and Ensuring that end of life care is supportive of the needs of younger people with dementia and their families

What might this look like?	Who would need to be involved?	What would be needed to make it happen?
• **Minimum standard of what people should expect from GP in relation to advance plan etc.** • Assessment of capacity • **Dementia Awareness etc. for hospice staff in particular if a younger person is admitted** • All professionals to be trained • All professionals to communicate with each other • **Continuity of workers** • **More staff training** • Better benefits to ensure people can stay at home for longer • **Knowledge of Physical effects of Dementia** • Pre-planning for this	• Person and their family to start advanced planning with primary care • **Conversations start with LPAS** ○ Are legal professionals aware of health and welfare side of LPA enough to advise? • It is no 'one' person's role • Should it be part of assessment? • A 'professional' (or someone) to offer emotional support to family/children etc. • Care themes/residential services need to be age appropriate (+ involved in road map)	• Good communication between agencies • Knowing who is involved and who could be involved • Names of key people • How to contact key people • If end of life is approaching who decides when "procedures/actions" are implemented? • Family may not understand the person is moving into end of life and won't feel ready to face it • **Emotional support for people and their families and children and staff** • **Planning for future physical changes e.g. eating difficulties**

Appendix B

Name	Role/ Organisation
Steve Peak	Non- Executive Director, Worcestershire Health and Care NHS Trust (HACW)
Jenny La Fontaine	Young Onset Dementia Development Officer HACW
Hilary Thorogood	Team Manager Early Intervention Dementia Service HACW
Nick Stephens	General Manager - OA CMHT Wyre Forest, EIDS, Admiral Nursing, YOD & Continence Service HACW
Dr Bernie Coope	Consultant Psychiatrist -HACW
Dr Lathika Weerasena	Consultant in Old Age Psychiatry HACW
Dr Jacqui Hussey	Consultant Psychiatrist Berkshire
Claire Watts - Colleague of Dr Hussey	Occupational Therapist Berkshire
Felicity Richards	Consultant Psychiatrist -HACW
Anna Buckell	Clinical Psychologist EIDS HACW
Donna Hartshorne	EIDS Nurse HACW
Mel Palfrey	EIDS Nurse HACW
Tanya Knibbs	EIDS Nurse HACW
Rachael Hodgetts	Administrator to Jenny La Fontaine YOD Development Officer EIDS HACW
Jo Bowdler	EIDS Medical Secretary HACW
Carole Edwards	Nurse Consultant HACW
Nikki Hudson	CMHT Older People HACW
Margaret Shannon	Community Mental Health Nurse Older Adults - HACW
Genette Edmonds	Lead Nurse - Dementia and Older People Worcester Acute Hospitals NHS Trust
Linda Price	Assistant Clinical Lead for Dementia - Worcester Acute Hospitals NHS Trust
Helen Springthorpe	Admiral Nurse Team Leader HACW
Amanda Eley	Admiral Nurse HACW
Ruth Narramore	Student Doctor
Susan Davies	Clinical Co-ordinator, Studdert Kennedy House - HACW
Chris Russell	Senior Lecturer ADS University of Worcester
Dawn Brooker	Director ADS University of Worcester
Sue Pinfold-Brown	Contracts Manager ADS- University of Worcester
Nicola Jacobson	ADS - University of Worcester
Christine Carter	ADS - University of Worcester
Mike Watts	Senior Departmental Administrator- ADS University of Worcester

Jane Nicol	Senior Lecturer pre-registration nursing - University of Worcester
Elaine Skaljak	Specialist Dementia Mentor - Onside Independent Advocacy
Sarah Kane	Head of Community Engagement - Onside
Carol Rowley	Commissioning Manager Joint Commissioning Unit (JCU) Worcestershire County Council (WCC)
Catherine Quekett	Choice Checker Team JCU WCC
Alison Price	Choice Checker Team JCU WCC
Gill Carter	Dementia Advice Service Co-ordinator - Age UK
Anna Lomax	Occupational Therapist - HACW
Hanneke Monks	Occupational Therapist - HACW Worcester and North Wychavon
Anne Hancox	Specialist Speech and Language Therapy Manager HACW
Jo Scarle	Occupational Therapist HACW
Karen Parkinson	Speech and Language Therapist HACW
Lois Pena	Speech and Language Therapist HACW
Kerry Martin	Social Work Student
Liz Staveley	Head of Services, Age UK Worcestershire
Lorrain Cullen	Dementia Adviser Age UK Worcs
Shirley Bradley	Manager of Dementia Day Centre- Friends of the Elderly
Gill Read (Plus a team from Alzheimer's Society who assisted on the day)	Service Manager - Alzheimer's Society and AL's Café facilitator
Liz Comerford	Dementia Support Worker - Alzheimer's Society
Sue Day	Dementia Support Worker - Alzheimer's Society
Jo Weir	Support group facilitator - Alzheimer's Society
Tessa Gutteridge	Young Dementia UK - Oxfordshire
Bernard Feehan	Alzheimer's Society
Shelley Lewis	Staff Nurse - St Richards Hospice
Val Wellings	Education and Learning Facilitator - St Richards Hospice
Lisa Laurie	St Richards Hospice
Jo Linford	IAS Project Manager WAC
Mary Slater	WAC
Jo Phelps	Dementia Lead - Sanctuary Care
Camilla Lindo	Sanctuary Care
Nick Gayton	Aspire Active days

Jan Brant	Vulnerable People Project - H&W Fire and Rescue Service
Gill Pinder	Education - H&W Fire and Rescue Service
Mark Hamer	Managing Director - Home Instead Senior care Worcester
Richard White	Stanfield Nursing Home
Pat Morris	Stanfield Nursing Home
Charlotte Kelly	Solicitor - Thursfields Solicitors
Sarah Ingles	Solicitor - Thursfields Solicitors
Gill Goldfinch	Carers' Unit WCC
Clare Scott	Carers' Unit WCC
Peter Davies	Project Support Worker - Well Connected
Clair Rogers	ACT - Association for Care Training
Liz Weir	Occupational Therapist HACW
Sarah Styler	Support Worker
Claire Thornley	Occupational Therapist
Simon Patient	Care Home Manager - Heritage Manor