Worcestershire Health and Care NHS
NHS Trust

worcestershire countycouncil

Living Well With Young Onset Dementia;

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

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An Accessible Summary

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Acknowledgements

There are a number of people who should be thanked for their contributions to the consultation process.

First and foremost amongst these are the younger people with dementia and their families who have given their time and shared their experiences. We recognise the difficulties that this can sometimes bring and are very appreciative of your willingness to be open and honest.

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Introduction

During November and December 2013, consultations with younger people living with dementia and their families occurred, concerning their experiences and needs.

We asked people to consider the answers to two 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

41 Families including many younger people with dementia contributed their experiences and concerns. I am very grateful for the commitment and time people gave to meet with me.

Three main areas were considered:

- 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

The Early Experience of Symptoms

Concerns expressed included;

- That many people felt that their symptoms were not recognised or understood at an early point, and their concerns were not acknowledged
- Early diagnosis was not common; many had contact with numerous professionals before receiving a diagnosis. This often took a long time.
- Many people did not feel supported through this process of assessment and diagnosis and found it distressing and difficult
- Following diagnosis many people felt that they were left to cope alone without information, support and advice

A range of needs were identified, which are summarised in the table below;

Theme	• Needs
To understand and have an explanation about the symptoms being experienced	• To be believed and taken seriously • To be referred to a service that has expertise in young onset dementia • To have a choice about whether I want an assessment • To have an assessment and then an explanation of my symptoms • To feel supported through the process of assessment and diagnosis
To have a diagnosis when the time is right for me and my family	• To have an accurate diagnosis, the truth, from knowledgeable professionals • To adjust to the emotional impact of the diagnosis of dementia • To understand what is happening and what might happen, depending on how much I/ we want to know
To begin to live my life as I wish to	• To be respected • To be able to do the things that make life meaningful for me • To have purpose in life and to remain independent • To be able to talk about my feelings if I need that • To have enough information to help me to cope and manage my difficulties • To be financially secure • To maintain the relationships that are important to me • To have fun! • To feel supported and to know where to get help when I need it.
That my Family Members/ significant others needs are met too	• To understand what is happening and where to get help when we need it • Emotional support to adjust to the implications of the diagnosis together and separately • To have financial security • That children and young people have information and support

Living with Young Onset Dementia

Concerns expressed included that many people felt that;

- Their experiences and needs were not recognised and understood, and that this made it difficult for them to live their lives as they wished to
- They were left alone to cope with the consequences of the diagnosis without adequate information and support. This often meant that they did not know what services and support they could receive or how to access it
- They wanted to continue to have meaningful and purposeful lives but that there were many obstacles to achieving this, including the lack of local and available activities, volunteering and work based opportunities
- The main source of information and support came from people who live with dementia and their families, however many people described not being aware of this support and finding out about it by accident. Furthermore, it was felt that this should not be the only source of information and support
- Support for other family members, particularly children and young people was not available

A range of needs were identified which are summarised in the table below;

Theme	Needs
I need to have a purpose in my life, I want to carry on as normal for as long as possible	• I need to do things that give me a sense of purpose and achievement, and have fun • I need to maintain my self-respect • I want to have choices about what I do and what is important to me • I need to have accessible means of getting to work/ activities that I enjoy
I need to feel that I am of value	• I want to be treated with respect and not spoken down to. • I want to maintain the roles I have in life • I need to maintain my independence for as long as possible • I want my views and needs to be heard and responded to • I need to feel that I am not alone and that I am heard and believed

	• I need peace of mind and heart
I need to maintain the relationships I have with people I care about	• I want to be able to continue to have relationships with those people who are important to me • I want to have a normal family life • I need to share with others who understand my experiences
I need to feel secure	• I want to be financially stable • I want the local community and services in that community to support me to remain independent • I need structure and routines that help me to cope • I need to have people around me who understand me and my routines • I would like to feel well emotionally and physically • I need to understand what is happening to me and to have ways of managing these challenges • I need to be able to sleep well
It's important to me that my family and the people I care about are OK	• I want my family to have the support they need • We may benefit from time apart from each other as well as time together • We need information and support to understand what is happening • We need to know who to approach for support and where to go when this is needed • We need to be able to sleep well • We need to have fun • We need to feel that we are not alone • We need to be heard and 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

Increasing need for care

Concerns expressed included that many people felt that;

- A co-ordinated approach was needed between professionals and that this didn't often happen
- This was a difficult time, in which life changing decisions often had to be made. Many people felt alone and isolated when having to make these decisions
- They did not know who to talk to or where to go to get help and support
- Getting an assessment of their needs was a difficult process and not straightforward. Many people mentioned barriers to getting access to help and support.
- There is a lack of local support that is specifically developed to meet the needs of younger people with dementia and their families, including opportunities for meaningful activity through to care home provision.
- That professionals and carers did not always understand the needs and challenges facing younger people with dementia and their families and were not able to provide information and support when this was needed
- Continuity of care between professionals and carers was needed but often did not happen
- Personal and physical care needs were not always met appropriately

A range of needs were identified which are summarised in the table below;

Themes	Needs
We need to be heard and believed	• That we are treated with respect and dignity • That our perspectives (individual and shared) are listened to • That we are treated as partners in care
Knowledge and skills of professionals and carers concerning young onset dementia	• Professionals, services and carers understand about young onset dementia and how it impacts upon our lives • 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
A timely assessment of need	• To know how to get an assessment of need • That the process of assessment is understandable • That all of my needs are assessed as appropriate • That we are kept informed on the progress of assessment and how long it will take • That we understand the outcomes of assessment • That our financial circumstances are assessed appropriately
That we have choice	• We are given appropriate information about the services that are available • That I am involved in decision making where this is possible • I/ we are able to make informed choices about the services that we receive
Advance planning	• That we are able to plan for the future • That we have emergency plans
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
Care provision that is appropriate to the needs of younger people with dementia and their families	• That I have meaningful activity and occupation that is responsive to my individual needs • 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 • 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
My physical/ personal care needs are met	• My need for personal care is met with respect for me as an individual • My physical health needs are recognised and responded to appropriately
Continuity of provision	• That I know who the professionals and services are that are involved in my care • That I know who to contact to discuss concerns and get the support I need • Where I need this, I have a familiar team of people supporting me in my everyday life, who know me and know how to help me
Coping with the impact of dementia on our lives	• I and my family have support when we need it to cope with the emotional, social and practical impact of dementia upon our lives

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.