DEEP workshop @ Young Onset Dementia conference
30th September 2014, St Hughes College, Oxford

What are the issues facing younger people with dementia?
What are their priorities for action?

13 people with dementia took part in a DEEP workshop at the Young Onset Dementia conference in September.

These are the issues they said are important to them:
• “The government doesn’t recognise younger people with dementia”

• “The benefits system is not set up, the processes can’t cope with you if you are younger. There is an assumption that you are scrounging.”

• “You’ve got all the financial worry on top of having dementia”

• “Not only is the financial support tricky, but what happens if you want to carry on working - there is no flexibility in the system.”

• “We need to educate government agencies, society, services about young onset dementia issues.”

• “I was assumed to be fit for work - it was very stressful.”

• “We are not scrounging when we apply for incapacity benefit.”

• “Issues facing younger people need to highlighted in government strategies and documents and policies.”
• “There needs to be specialist, safe and social accommodation for younger people with dementia.”

• “It would be good to have ‘extra care solutions’ with staff/people who will stay with you and build relationships.”

• “Where do we go if we need respite? I don’t want to be in an old people’s home.”

• “I was refused housing as I was too young.”

• “It’s a struggle living alone.”

• “We need to build grass roots initiatives - dementia friendly communities, engage with local councillors, local MPs, dementia friends.”

• “Local activities for younger people with dementia need to connect together.”

• “We want to be in the middle of communities and activities - not segregated.”

• “Helpful technologies should be made available and better known to people with young onset dementia.”

• “You need to get support for personalised coping strategies.”
“You need to go ‘out there’ - get yourself on committees, speak out on young onset dementia issues.”

“We need to raise awareness of young onset issues - point out our different needs and also demonstrate what younger people with dementia can still do.”

“We are not recognised.”

“We need to educate youngsters in schools about dementia.”

“We need to send out the message - look what we can do.”

“There are implications when you come back out. You can't go back in. This can be a problem for your children.”

“Working together we can achieve more. A network would be good.”

“We need to educate GPs on referring younger people for a diagnosis.”

“Doctors don't want to know about us. They expect it with older people.”

“We need to get GP’s to become more innovative.”
• “We don’t want to be vulnerable”

• “I want to take risks - cooking, living alone.”

• “I want to know about it all - they assume it’s all older people, and that they don’t want to know.”

• “We need to share our coping strategies with each other.”

• “I was disbelieving at first. It was frightening.”

• “We want treatment as well as medication. This might be walking, art, music.”

• “Complete collapse can be avoided by early support.”

• “Sometimes you feel very vulnerable.”