

## G.13 Needs of younger people living with dementia

### G.13.1 The specific needs of younger people living with dementia

#### Review question

- What are the specific needs of younger people living with dementia?

#### G.13.1.1 CERQual tables

##### Themes identified for employment: experiences and coping

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: PWD: An awareness of changes in their functioning in the work place as they developed dementia.							
1 (Chaplin 2016)	Interviews	For three participants, the Engineer, the Businessman and the Schools Meals Assistant, the first signs were poor short-term memory and a difficulty in remembering names and adjusting to new tasks.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Shock at losing their expected future.							
1 (Clemerson 2014)	Semi-structured interviews	For many, this included loss of employment as they were forced to take early retirement.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: A reluctance to acknowledge the signs							
1 (Chaplin 2016)	Interviews	All of the participants described how they did not initially think that these difficulties in specific areas of functioning were the first signs of something more serious. At this stage, they tended to ascribe the changes to pressure of work, new work roles, life-long traits, such as poor memory or declining physical skills such as poor eyesight	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Sharing the fears							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Chaplin 2016)	Interviews	They then began to suspect it was something more serious and all discussed their difficulties with their partners and were encouraged to seek further help.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Self-management							
1 (Chaplin 2016)	Interviews	Three of the participants were able to discuss strategies for managing the symptoms of their illness in the workplace. They all spent more time and effort in planning and organising tasks and acknowledged how difficult it could be even with these strategies in place	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Feeling under scrutiny							
1 (Chaplin 2016)	Interviews	The three participants who worked more closely with others described how their managers or colleagues had noticed that they were having difficulties in some tasks. They mainly tried to manage this by increased observation of the employee but did not discuss this with the employee. Consequently, the participants felt that they were being watched covertly and they would have preferred to have been consulted about this.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: A lack of consultation about management decisions							
1 (Chaplin 2016)	Interviews	Though two of the participants were given some adjusted duties when their employers became aware that they were having difficulties, none of the participants said that they were offered any 'reasonable adjustments' to their work role under the Equality Act (2010) after diagnosis. None of the participants were referred to a Disability Employment Advisor by their workplace. The HGV Driver and the School Meals Assistant were advised to take sickness leave when their employers became aware of the extent of their difficulties at work. They were advised to seek further assessment of their difficulties from their GP. Both of their GP's did make referrals on, one to a Neurologist and one to a Psychiatrist. Both these participants were then on	Not serious	High	High	Low <sup>1</sup>	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		sickness leave for the full six months and never returned to work					
Theme: PWD: A belief in continued competence despite the realisation of impairment							
1 (Chaplin 2016)	Interviews	Three of the participants felt that they would have been able to carry on with an adjusted work role when they were diagnosed with dementia, while the School meals Assistant and the Businessman believed that they were no longer competent.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Feeling abandoned by the workplace and consequent feelings of resentment towards the workplace							
1 (Chaplin 2016)	Interviews	Three of the participants expressed feelings of abandonment in how their employment situation was managed by their workplace. They felt that when they received their diagnosis and informed their workplace, no real attempt was made to find any adjusted work role for them.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: An acceptance of the final outcome							
1 (Chaplin 2016)	Interviews	Four of the participants expressed an acceptance of the final outcome of their employment	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Coming to terms with their situation							
1 (Chaplin 2016)	Interviews	Two of the participants are now on Employment Support Allowance, one has taken early retirement and two classed themselves as semi-retired. Four of the participants said that their work was a big part of their life and that they had enjoyed it and taken a pride in doing it well.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Financial hardship and consequent worry							
1 (Chaplin 2016)	Interviews	All of the participants said that leaving work had affected their family and their relationships. The Nursing Assistant and the HGV Driver both had partners who are still working and they had taken on more domestic roles to help them. For the HGV Driver and the School Meals	Not serious	High	High	Low <sup>1</sup>	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		Assistant, leaving work had meant some financial hardship and consequent worry					
Theme: PWD: A positive outlook for the future							
1 (Chaplin 2016)	Interviews	Despite their difficult experiences all of the participants were determined to be positive about their future. All of the participants said that they had taken up new hobbies or restarted old ones since leaving or reducing their work. The three participants who are under the age of 65 had been referred to the Young Onset Dementia Service in their local area and had become involved in the various social and leisure activities facilitated by this service.	Not serious	High	High	Low <sup>1</sup>	Low
1. This is the only UK study that addresses this theme, and contains only a very small numbers of participants.							

### Themes identified for general experiences and coping

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: PWD: Relief at getting the diagnosis confirmed							
1 (Clayton-Turner 2015)	Interviews	Relief at getting the diagnosis confirmed	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: PWD: Feelings of shock and a sense of loss at receiving the diagnosis							
1 (Pipon-Young 2012)	Interviews, group discussions	Feelings of shock and a sense of loss at receiving the diagnosis	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: Experiences of feeling 'too young'.							
2 (Clemerson 2014, Pipon-	Semi-structured interviews, interviews,	What surprised people was their age at diagnosis, with the general assumption that dementia was something affecting older people.	Not serious	High	High	High	High

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Young 2012)	group discussions						
Theme: PWD: Ambiguity of the term 'younger people with dementia'							
1 (Pipon-Young 2012)	Interviews, group discussions	Ambiguity of the term 'younger people with dementia', and people being unsure whether the label applied to them	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: Younger people living with dementia often have responsibility for children, a mortgage or a business to run							
1 (Pipon-Young 2012)	Interviews, group discussions	Younger people living with dementia often have responsibility for children, a mortgage or a business to run	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: People coped by normalising the situation.							
1 (Clemerson 2014)	Semi-structured interviews	Creating an identity as an older person, even transiently, allowed people to make sense of developing AD by normalising the life-cycle.	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Telling children about the diagnosis is difficult							
1 (Clayton-Turner 2015)	Interviews	Telling children about the diagnosis is difficult, particularly at an age when they will not have been expecting it	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: PWD: Developing dementia forced people to contemplate death.							
1 (Clemerson 2014)	Semi-structured interviews	Developing dementia forced people to contemplate death	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Shock at losing their expected future.							
1 (Clemerson 2014)	Semi-structured interviews	For many, this included loss of employment as they were forced to take early retirement	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Loss of adult competency.							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Clemerson 2014)	Semi-structured interviews	Loss of adult competency represents another sub-theme in the disruption to the life-cycle. This emerged through people's experience of either feeling more 'childlike' due to a loss of skills or being treated this way by others	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Some people tried to prevent themselves from thinking about the future.							
1 (Clemerson 2014)	Semi-structured interviews	Some people tried to prevent themselves from thinking about the future	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Some people tried to stay positive, which for a few meant denying further significant decline.							
1 (Clemerson 2014)	Semi-structured interviews	Some people tried to stay positive, which for a few meant denying further significant decline	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: With further reflection it seemed that some participants were working towards resolving concerns through comparing their situation to others who were more impaired or died younger than themselves.							
1 (Clemerson 2014)	Semi-structured interviews	With further reflection it seemed that some participants were working towards resolving concerns through comparing their situation to others who were more impaired or died younger than themselves.	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Redefining self							
2 (Clemerson 2014, Pison-Young 2012)	Semi-structured interviews, interviews, group discussions	Acknowledging change. Descriptions of the experience of dementia often related to changes people experienced, particularly in relation to what they could no longer do, a loss of independence or how their life had changed. This included a loss in social status and an inability to carry out everyday tasks.	Not serious	High	High	High	High
Theme: PWD: All participants referred to their concerns of what may happen as their dementia progresses. This concern arose in response to meeting others with more advanced dementia.							
1 (Pison-Young 2012)	Interviews, group discussions	This concern arose in response to meeting others with more advanced dementia. It was also frightening for	Not serious	High	High	Low <sup>3</sup>	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		people to imagine a time when they may not realize their memory was deteriorating.					
Theme: PWD: Often raised was the negative impact of others' perceptions.							
1 (Pipon-Young 2012)	Interviews, group discussions	Typically described were the negative perceptions of the word 'dementia', resulting in a lack of understanding about dementia and a loss as to how to be with people with dementia. A number of misconceptions were described regarding others' understanding of dementia. There seemed to be a sense that there was an avoidance of a true understanding in order to prevent painful truths.	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: A reduced sense of self-worth also contributed to the threat to self.							
1 (Clemerson 2014)	Semi-structured interviews	Simply having the disease made some individuals question their worth.	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Most participants who disclosed their condition had positive responses from others, which helped them to accept their diagnosis as part of who they were.							
1 (Clemerson 2014)	Semi-structured interviews	Most participants who disclosed their condition had positive responses from others, which helped them to accept their diagnosis as part of who they were.	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Holding on to their existing self-concept.							
2 (Clemerson 2014, Pipon-Young 2012)	Semi-structured interviews, interviews, group discussions	Nearly all participants raised the importance of acknowledging that although they have dementia, there were many aspects of their lives that remained the same.	Not serious	High	High	High	High
Theme: PWD: Many participants described ways in which they covered up their dementia.							
1 (Pipon-Young 2012)	Interviews, group discussions	Reasons for this surrounded the uncertainty of others' reactions and perceptions of them. Participants described wishing others would keep seeing them as the person they always were and 'normal'.	Not serious	High	High	Low <sup>3</sup>	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: PWD: Other people saw it as better to tell others that they had dementia, so they could understand their difficulties.							
1 (Pipon-Young 2012)	Interviews, group discussions	Other people saw it as better to tell others that they had dementia, so they could understand their difficulties.	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: Participants spoke of the importance of remaining independent, active and involved.							
1 (Pipon-Young 2012)	Interviews, group discussions	This could be achieved by finding a reason to keep fighting and not only focusing on deficits.	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: Many participants spoke of the importance of knowing other people with dementia and being able to share understandings through similar experiences.							
1 (Pipon-Young 2012)	Interviews, group discussions	Many participants spoke of the importance of knowing other people with dementia and being able to share understandings through similar experiences.	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: Participants described support from partners, friends, family, services, professionals, and through faith and spirituality.							
1 (Pipon-Young 2012)	Interviews, group discussions	Participants described support from partners, friends, family, services, professionals, and through faith and spirituality.	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: Resilience							
1 (Pipon-Young 2012)	Interviews, group discussions	There was a sense from participants that being diagnosed with dementia was not a helpless situation. There were still things they could do for themselves.	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: Participants discussed keeping their brains stimulated							
1 (Pipon-Young 2012)	Interviews, group discussions	Participants discussed keeping their brains stimulated.	Not serious	High	High	Low <sup>3</sup>	Low
Theme: PWD: Disconnection and isolation							
1 (Clemerson 2014)	Semi-structured interviews	A shared phenomenon of feeling isolated or disconnected from others emerged, which is heightened by a lack of age-appropriate services.	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Re-engaging in life following people's initial experience of disconnection and isolation.							



Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Clemerson 2014)	Semi-structured interviews	Although disconnection was identified as a way of managing the sense of difference to others, it was recognised that this could not be sustained long term	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: As people began to reconnect with others, their focus shifted.							
1 (Clemerson 2014)	Semi-structured interviews	Their focus shifted from concern with how they cope to concern with how their loved ones cope. Others focused their attentions on contributing to the community and helping other people with dementia.	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: The intention to regain control emerged as a common coping strategy in response to the experience of loss of agency.							
1 (Clemerson 2014)	Semi-structured interviews	The intention to regain control emerged as a common coping strategy in response to the experience of loss of agency.	Serious <sup>1</sup>	High	High	Low <sup>3</sup>	Very low
Theme: PWD: Dementia Service User Network (otherwise known as the 'Forget-Me-Nots') provide social comradeship and are a useful resource							
1 (Clayton-Turner 2015)	Interviews	Dementia Service User Network (otherwise known as the 'Forget-Me-Nots') provide social comradeship and are a useful resource	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: PWD: Making the most of life							
1 (Clayton-Turner 2015)	Interviews	Receiving a diagnosis of a life-limiting condition tends to concentrate the mind. It helps you recognise what is important, clarifying life goals and helping you identify things you want to do. Dementia forces you to make the most of every day, to live in the moment and cherish times of fun, intimacy and discovery. You find a new strength within and a depth to some relationships which become closer through the hard times.	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: PWD: Younger people living with dementia find YoungDementia UK very helpful.							
1 (Clayton-Turner 2015)	Interviews	Younger people living with dementia find YoungDementia UK very helpful.	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: Carer & PWD: Having dementia is frustrating, concerning and induces fear							
1 (Clayton-Turner 2015)	Interviews	Having dementia is frustrating, concerning and induces fear, and caring for a young person with dementia is stressful.	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: Carer: There is a lack of support for younger people living with dementia and their carers.							
1 (Clayton-Turner 2015)	Interviews	There is a lack of support for younger people living with dementia and their carers	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: Carer: When caring for a younger person living with dementia, key to coping and staying well is to carve out time for self							
1 (Clayton-Turner 2015)	Interviews	When caring for a younger person living with dementia, key to coping and staying well is to carve out time for self	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: Carer: Carers can receive support online at Talking Point, a peer support community run by Alzheimer's Society.							
1 (Clayton-Turner 2015)	Interviews	Carers can receive support online at Talking Point, a peer support community run by Alzheimer's Society	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: Carer: A diagnosis of dementia should be made before stopping work.							
1 (Clayton-Turner 2015)	Interviews	Otherwise, a person may not get their full pension. If a person stops working because of sickness, they may get their full pension. In addition, a diagnosis might enable the person to continue working at a reduced role or with support	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: Carer: Driving should be discussed.							
1 (Clayton-Turner 2015)	Interviews	Driving should be discussed	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: Carer: Becoming involved with research is advantageous for younger people living with dementia and their carers.							
1 (Clayton-Turner 2015)	Interviews	Becoming involved with research is advantageous for younger people living with dementia and their carers	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
Theme: Carer: Younger people living with dementia benefit from having relationships that are allowed to develop.							
1 (Clayton-Turner 2015)	Interviews	Younger people living with dementia benefit from having relationships that are allowed to develop	Serious <sup>1</sup>	High	High	Moderate <sup>1</sup>	Low
<ol style="list-style-type: none"> <li>1. Theme only identified in studies at moderate risk of bias.</li> <li>2. This is the only UK study that addresses this theme.</li> <li>3. This is the only UK study that addresses this theme, and contains only a very small numbers of participants.</li> </ol>							

### Themes identified for a walking group for younger people living with dementia and their carers

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: PWD: The walking group created supportive and positive relationships, bringing closeness, friendship and compassion.							
1 (Hegarty 2014)	focus group interview, questionnaire	The walking group created supportive and positive relationships, bringing closeness, friendship and compassion.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Group members were clear about the benefits to partners							
1 (Hegarty 2014)	focus group interview, questionnaire	Group members were clear about the benefits to partners.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: PWD: Some talked about the disadvantages of having a large walking group.							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Hegarty 2014)	focus group interview, questionnaire	Some talked about the disadvantages of having a large walking group.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: Carer: Through the spouses' questionnaire, partners reported some positive impact on physical health and communication skills, and a substantial positive impact on mood.							
1 (Hegarty 2014)	focus group interview, questionnaire	Through the spouses' questionnaire, partners reported some positive impact on physical health and communication skills, and a substantial positive impact on mood.	Not serious	High	High	Low <sup>1</sup>	Low
1. This is the only UK study that addresses this theme, and contains only a very small numbers of participants.							

### Themes identified for a day service for younger people living with dementia

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: A sense of belonging							
1 (Higgins 2010)	Interviews	To feel part of a valued group, to maintain or form important relationships. An opportunity to simply 'be myself' and 'not pretend' are important to evaluative outcomes of a successful service.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: ACE club provided a sense of achievement.							
1 (Higgins 2010)	Interviews	It enabled members to reach valued goals to the satisfaction of self and/or others. In considering this sense and its place in their life, ACE club members took a broad viewpoint on inclusion, which included a focus on physical rehabilitation to promote health and well-being, and supported practical strategies for daily living to promote confidence and reaffirm roles within the home.	Not serious	High	High	Low <sup>1</sup>	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: ACE club enabled members to talk through their problems							
1 (Higgins 2010)	Interviews	ACE club enabled members to talk through their problems.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: ACE club provides a sense of purpose							
1 (Higgins 2010)	Interviews	ACE club provides a sense of purpose.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: A sense of security							
1 (Higgins 2010)	Interviews	To feel safe physically, psychologically, existentially. Many of the responses shared by members in the evaluation reinforce a sense of security on many levels. However, the inclusive nature of the membership of the ACE club strengthened the sense of security for the wider family and this was seen as a vital part of the service and the meaning that it held for members. The evaluation process demonstrated that group cohesion provided a sense of security for its membership where 'permission' to be vulnerable within a supportive environment was essential to human growth. Without this sense of security, some members feared that they would simply have to return to smaller family networks where their role and status may not be so well supported.	Not serious	High	High	Low <sup>1</sup>	Low
Theme: A sense of significance							
1 (Higgins 2010)	Interviews	To feel that you 'matter' and are accorded value and status. Interestingly, this was the 'sense' that was evaluated by the ACE club members as being the most important. Significance was experienced on a number of levels and with multiple meanings. The ACE club members valued the opportunities to speak at local, regional and national conferences with their campaigning voice for younger people with dementia, helping to spark and inform the development of a	Not serious	High	High	Low <sup>1</sup>	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		number of service philosophies and initiatives across the country, as well as inspire similar clubs in Australia, namely CALM and ConnexUS in Adelaide, South Australia. Additionally, members saw the significance of being involved in teaching clinical psychology students and student nurses. This sense of significance cascaded through their lives both at home and within the wider community and enhanced their experience of living and reaffirmed their sense of self.					
Theme: ACE club was felt to slow down the progression of dementia							
1 (Higgins 2010)	Interviews	ACE club was felt to slow down the progression of dementia.	Not serious	High	High	Low <sup>1</sup>	Low
1. This is the only UK study that addresses this theme, and contains only a very small numbers of participants.							

### Themes identified for a lunchtime social group for younger women living with dementia ('Ladies who Lunch')

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: PWD: Ladies who Lunch provided value to those attending it							
1 (Johnson 2008)	Written and verbal feedback	Ladies who Lunch provided companionship, a relaxing atmosphere, was enjoyable and was valued by bot the women and their carers.	Serious <sup>1</sup>	High	High	Moderate <sup>2</sup>	Low
Theme: Carer: Ladies who Lunch gives younger women living with dementia greater confidence							
1 (Johnson 2008)	Written and verbal feedback	Ladies who Lunch gives younger women living with dementia greater confidence.	Serious <sup>1</sup>	High	High	Moderate <sup>2</sup>	Low
<p>1. Written and verbal feedback is likely to result in data from motivated participants. Less motivated participants' views might not have been forthcoming and those views could be valuable. There was no before and during comparison. Inclusion and exclusion criteria are not provided; nor are characteristics of the participants.</p> <p>2. This is the only UK study that addresses this theme.</p>							