

# What are the Specific Needs of a Service User Living with Early Onset Dementia?



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## Abstract

This study reviews the literature on the needs of people living with early onset dementia. Nine relevant studies on this topic have been included and reviewed. The main findings are: there are not enough age appropriate services, there is a need for early and accurate diagnosis in early onset dementia, and due to the people living with early onset being younger people have work and relationship needs that need addressing. It also discusses how a multi disciplinary approach and expertise can help with the above and supporting people living with early onset dementia. The study also highlights the need for further research in this field and possible improvements in the diagnostic period.

**Keywords:** Early onset dementia is anyone with dementia under the age of 65; Multi disciplinary approach is an approach that had many different professionals to work together

## Introduction

According to the Alzheimer's Society (1) 17,000 people live with early onset dementia, this figure is also believed to be grossly under estimated. Early onset dementia is defined as anyone with dementia under the age of 65 [1-11]. The most common forms of early onset dementia are: Alzheimer's disease, frontal temporal dementia and vascular dementia there are many more types which are more unique to early onset such as Alcohol related dementias [1]. According to Bentham and La Fontaine [9] services are slowly growing but possibly still not adequate for the needs in early onset dementia [4,8,9,10,12].

## Methodology

The purpose of this literature review is it to identify the service needs of people living with early onset. This literature review aims to inform the reader about the recurrent need of people living with dementia and possibly lead to improvement in caring for people with early onset dementia through the gained knowledge of their needs.

The initial search began with the difference between early onset and late onset dementia but the search results was very limited therefore I broadened the search to just the needs of people living with early onset dementia. To conduct the search E-Resources within the University of Worcester's portal was used, then Health as a subject was chosen and included results

from: Academic search complete, Cumulative Index to Nursing and Allied Health Literature database, Medline database and psy ARTICLES.

The search terms which came up with the most relevant results were 'early onset dementia' and 'needs', the search came up with twelve articles which mention care provision in early onset dementia but a large number where unavailable. Then the search term 'pre-senile dementia' and 'needs' was used which came up with some relevant results. After saving all the articles in a temporary folder the abstracts was read and the most relevant to the review was handpicked. A limitation of the search was that some articles after the initial search was unobtainable such as being unavailable though the universities infrastructure such as e-resources and summon.

## Results & Discussion

Please see Table 1. This study has attempted to identify and discuss five key themes that occur most in the articles in this literature review. The five themes that have been identified are: Age appropriate services, accurate and timely diagnosis, Employment and financial issues, family and sexual relationships and a multidisciplinary approach and expertise in early onset dementia care. The aim in the discussion is to explore the heading and attempt to understand and review the needs of people with early onset dementia.

**Table 1:** This study has attempted to identify and discuss five key themes that occur most in the articles in this literature review.

Author and date	Name of article	Type of article/ Methods used	Sample size if applicable	Summary of main themes	Summary of critical appraisal
Tindall,L and Manthorpe,] [11]	'Early onset dementia: A case of ill-timing?	Literature Review	Not specified	<ul style="list-style-type: none"> <li>Quicker progression and possibly more impaired than people with late onset dementia</li> <li>family links and genetic counselling</li> <li>the need for early diagnosis to allow possible treatment, management of legal and personal affairs and early support</li> <li>the need to support the person who maybe suffering from stress, grief and depression</li> <li>the need for support in relationships between people in the outside world and in the family such as family counselling</li> <li>the need for age appropriate services due to people being 'fitter' also wanting to mix with their own age group</li> <li>More appropriate activities and support such as employment, family care and domestic activities.</li> <li>the need for support in sexual relationships</li> <li>The need for support with coping with the disease and disability due to more insight into what's happening.</li> <li>Quicker decline so more help with coping with this</li> <li>The need for multi disciplinary and inter disciplinary action</li> <li>Respite care for example age appropriate day centres.</li> <li>The need to reduce the stigma of mental health in society</li> </ul>	<ul style="list-style-type: none"> <li>No literature sample size included</li> <li>Appropriate literature accessed</li> <li>Critical appraisal is evident in the article. Relevant to my literature review.</li> </ul>
Chaston,D [8]	Between a rock and a hard place: Exploring the service needs of younger people with dementia	Literature Review	19 studies included	<ul style="list-style-type: none"> <li>Age appropriate services and the need to mix with people of their own age group.</li> <li>Services that can cope with people who are generally fitter, stronger and healthier.</li> <li>Higher rates of anxiety in early onset dementia.</li> <li>The need to include family in decision making due to their being more family involved.</li> <li>Financial needs and employment issues with people living with early onset dementia.</li> <li>The need for early diagnosis and early access to services</li> <li>Help, support and counselling needed to enable people to cope with the condition.</li> <li>A multi disciplinary team to work with the person with dementia.</li> </ul>	<ul style="list-style-type: none"> <li>Fairly limited sample sizedue to limited literature in this field .</li> <li>Very relevant to my study</li> <li>Critical appraisal of literature is evident.</li> <li>Appropriate literature accessed</li> </ul>
Van Vliet, D , De Vugt, M , Bakker, C , Koopmans,R , Pijnenburg,Y , et al. [10]	Caregivers' perspective on the pre diagnostic period in early onset dementia: a long and winding road	Research article Semi structured interviews, Comparative analysis and grounded theory. Qualitative study	92 carers	<ul style="list-style-type: none"> <li>Early diagnosis to allow better understanding of the disease and possible future planning</li> <li>Early onset dementia often causes stress and depression which needs addressing.</li> <li>The need for support in employment.</li> <li>The need for understanding of dementia especially from family and friends.</li> </ul>	<ul style="list-style-type: none"> <li>This is a caregiver's perspective; according to Chaston (2011) service user's perspective is more valuable information.</li> <li>Relevant to literature review</li> <li>Fairly large sample</li> </ul>

Barber, R [13]	A Survey of services for younger people with dementia	Research article Postal survey Qualitative study	304 trusts	<ul style="list-style-type: none"> <li>The need for clinical leaders and multi disciplinary approaches.</li> <li>Age appropriate services.</li> <li>The needs for specific care pathways and communication between services to allow for appropriate care.</li> </ul>	<ul style="list-style-type: none"> <li>Only discusses services available not all needs.</li> <li>Critical appraisal evident</li> <li>Large sample</li> </ul>
Beattie, A M , Daker-White, G , Gilliard, J and Means, R [6]	Younger people in dementia: a review of service needs, service provision and models of good practise.	Literature review	74 articles	<ul style="list-style-type: none"> <li>The need for support with employment, and financial needs such as benefits and pension.</li> <li>The need to address low self esteem and depression.</li> <li>Younger people with dementia are generally younger and fitter and have a greater insight into their condition.</li> <li>Sexual and relationship needs in people with early onset dementia.</li> <li>Need for age appropriate services.</li> <li>The need for a multi disciplinary approach</li> </ul>	<ul style="list-style-type: none"> <li>Very relevant to study</li> <li>Critical appraisal evident</li> <li>Large sample</li> <li>Appropriate literature accessed</li> </ul>
Bentham, P and La Fontaine, J [9]	Services for younger people with dementia	Journal article	N/A	<ul style="list-style-type: none"> <li>The need for a multi disciplinary approach</li> <li>A person centred approach is vital in younger people.</li> <li>The need for respite care</li> <li>Age appropriate services , younger and stronger people don't mix well with older people with dementia</li> <li>Support with Employment issues and benefit and pensions</li> <li>Independence is important in early onset dementia</li> <li>Counselling and support with coping with the disease.</li> <li>The effect on the family</li> <li>The need for investigation and diagnosis of the disease</li> </ul>	<ul style="list-style-type: none"> <li>Not much critical appraisal evident due to nature of article</li> <li>Relevant to study</li> </ul>
Ferran J, Wilson K, Doran M, Ghandiali E, Johnson F, [5]	The early onset dementias: A study of clinical characteristics and service use	Research article Examination of case notes Qualitative study	200 case notes	<ul style="list-style-type: none"> <li>The need for a accurate diagnosis to allow the person to plan for their future care.</li> <li>A multi disciplinary team in diagnosis and supportive</li> <li>The possible need of age appropriate service due to homes generally catering for older residents case.</li> <li>The need for expertise in early onset dementia to offer better support.</li> </ul>	<ul style="list-style-type: none"> <li>Mainly focused on service use and not all the needs of people living with early onset dementia</li> <li>Fairly large sample size</li> </ul>
Harris, P and Keady, J [12]	Selfhood in younger onset dementia: transitions and testimonies	Research article Interviews Qualitative study Grounded theory	38 precipitants	<ul style="list-style-type: none"> <li>The need for a early diagnosis</li> <li>The need for support with family changes, work issues and retirement/financial issues</li> <li>Support in sexual relationships and to be able to admit to need help in sexual relationships</li> <li>Support in coming to terms with their decline</li> <li>The need for a diagnosis and supporting stress at this time.</li> <li>The need for help and support in the community so people don't feel isolated.</li> <li>Reducing stigma and normalizing services to support people with early onset dementia</li> <li>Age appropriate services needed</li> <li>The need to allow people living with early onset dementia to express their own needs</li> </ul>	<ul style="list-style-type: none"> <li>Compared to other studies small sample size but well analysed</li> <li>Very relevant to study</li> </ul>

Beattie, A M , Daker-White,G , Gilliard,J and Means, R [7]	How can they tell? A qualitative study on the views of younger people about their dementia and dementia care services	Qualitative study Interviews Grounded theory	14 precipitants	<ul style="list-style-type: none"> <li>the need to address possible feelings of isolation, low self esteem and depression</li> <li>age appropriate services due to people with early onset dementia possibly being physically fitter than older people,</li> <li>Also due to the need for age appropriate service is so that younger people with dementia can engage and interact with people of their own age as well as conducting meaningful activities.</li> <li>maintaining sexual relationships can be an issue</li> <li>work issues and pension and financial issues may place strain on the family</li> <li>The need to involve the people in their own care as well as the importance for their views to be heard with support.</li> <li>The need to be treated 'normally' and as 'ordinary people'</li> <li>The need for a more timely diagnosis and the possible need for it to be conducted and given more sensitively</li> <li>the importance of people with dementia to stay independent</li> <li>importance of person centred care</li> <li>rapid progression and loss of cognitive ability means the family is important in decision making</li> <li>inter disciplinary approach is important</li> </ul>	<ul style="list-style-type: none"> <li>Compared to other studies small sample size but well analysed</li> <li>Focused on the views of the service user which is looked highly upon (Chaston 2011)</li> <li>Relevant to study</li> </ul>
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### Age appropriate services

Age appropriate services could be perceived as a very general need for people living with early onset dementia but it is one of the most occurring themes within the literature accessed in this review. Through reading through the literature it is apparent that it is common for younger people even as young as 20-30 to be admitted to homes catering for older people [11] which is considered by many as a problem .

In Tindall and Manthorpe and Chaston [8,11] it states that younger people are generally fitter therefore do not mix well with older more fragile people this is echoed in Beattie et al. [6,7,9], Where it also states that age appropriate services are important in helping people to cope with their condition due to a greater insight into their condition. Another issue of younger people living with dementia being in an older setting is that they are often mistaken as carers and social workers within the setting [6] and also according to Beattie et al. [7] younger people who are placed in services for older people with dementia tend to take a caring role towards the older more frail residents.

In Adams and Manthorpe [4] it states that there is a need for more comparisons between basing services on the individual needs of people with early onset dementia and their age needs, in Beattie et al. [7,8] It touches on this issue but there is a need for further development in which would be more successful and appropriate care in early onset dementia, this fits into the view in Bentham and la Fontaine [9] that due to the low occurrence of early onset dementia age appropriate services would be too costly to implement, so individualised and need specific services could be more viable . According to Beattie et al. [6] a more community based service could be more appropriate to cater for the individual needs of people living with early onset dementia.

According to Chaston [8] it states that services that are not appropriate to their needs could cause faster decline in their condition, in [7] it emphasises the importance of more appropriate and engaging activities for the people living with early onset dementia to conduct. It is also explored in Adams and Manthorpe [4] that people living with dementia often have unmet social needs so having age appropriate services will allow people living with early onset dementia to communicate with people of tier own age.

Beattie [7] discusses the idea of people being lost between services due to limited age or need appropriate services. It is apparent that within some of the literature [9,13], it argues with the general belief that there is a lack of age appropriates services ,instead, it states that there is a lack of organisation and co ordination within early onset service provision.

According to Adams and Manthorpe [4] there is a lack of comparison studies that compare age appropriate services and need specific services, this is apparent in this study where some of the articles touch on the idea of need appropriate services but does not compare them in detail.

### Accurate and timely diagnosis

Accurate and early diagnosis is vital in early onset dementia due to it allowing for early treatment and allowing the person living with early onset to cope with the condition. It is a recurrent them that is mentioned in the majority of the articles included within this review. According to Vliet et al. [10] a timely diagnosis allows a person living with early onset dementia to come to terms and start understanding their condition, this is important because according to Adams and Manthorpe [4] it allows for the attainment of comprehensive information,

support and treatment. According to Chaston [8] early diagnosis is important in family dynamics and early access to services and support.

Early diagnosis also allows people to plan their life and deal with the diagnosis this can correlate with the life course theory. The life course theory is a way of exploring a person's influences, changes and transitions which are age related. The model has the concept of a life 'time table' which a disease such as dementia can effect a person's timetable [11]. Another consideration would be that according to [11] early onset dementia progresses quicker than late onset so due to this the earlier the condition is diagnosed the more chance of treating the disease. According to Harris and Keady [12] public awareness can help to recognise early signs of early onset dementia, therefore the earlier the signs are recognised it could be argued that a person could get seek help earlier and get an early diagnosis. In Harris and Keady [12] it states that people find it hard to admit they have problems so this could deter people seeking help and therefore not seeking help and a timely diagnosis, this is where counselling and therapy could help with people building up the confidence to seek help [9].

There is the need for General practitioners (GP's) to take the symptoms of dementia in young people seriously to allow for timely and accurate diagnosis given more sensitively [6,8,9]. According to Tindall and Manthorpe [11] GP's are less likely to diagnose a person with dementia due to its low prevalence. Diagnosis in early onset dementia is difficult because at times the symptoms could be intermittent and the symptoms could be assassinated to non medical conditions [11]. Diagnosis of the correct type of dementia is a problem according to Ferran et al. [5] which states that nearly a third of people get diagnosed with unspecified dementia.

According to [8,10] carers feel as though they are pushed from consultant to consultant and that the information of services and counselling is the burden of their carers' and family. In Tindall and Manthorpe [11] it states that people suffer from depression before the diagnosis so early diagnosis could cause less distress and harm to the person living with early onset dementia.

A reoccurring theme in the diagnostic period in the articles in this study is that it is the views of the carers, according to Chaston [8] the views of the person living with dementia are the most important in understanding the disease and in research and literature on dementia. There are a few articles that discuss the opinions of the service user but it seems to not be the general consensus.

## Employment and financial issues

Due to people being younger and possibly still working and having families to support employment and financial issues are an important issues to take into account in early onset dementia [12], most of the articles included in this review touch upon this

important issue that is relatively unique in early onset dementia compared to later onset dementia due to people being younger and possibly still in employment [4] Employment and financial issues do fit in with appropriate services but can be separated through the importance of the person living with early onset dementia possibly still being of working age.

Work issues and pension and financial issues may place strain on the family though the loss of jobs and work strain, stress can also come from the inability of the person living with early onset dementia to understand the importance of the condition and why they are having the difficulties at work [10]. The diagnosis helped with work due to the increased knowledge for the family of the person and the employer so support in the work place is obtainable [10] also a person's partner or spouse might have to cease work and become a full time carer', this can have major financial implications and cause relationship issues as well [11].

Need for employers to understand the needs for people living with dementia, this is emphasised in Bentham and La Fontaine [9] where it states that it is common for people with early onset dementia to be made redundant from work due to the symptoms of early onset dementia. Bentham and la Fontaine [9] also states that it is important for employers to recognise dementia as a reason for early retirement which would not affect benefits and pensions. The life course theory as mentioned above is relevant due to employment being a large stage of a person's life course [11] this possibly will cause unease as in age due to a person being in a life stage that is not relative to their age such as retirement this fits into the theory of normalisation and a person self view of normality [11]. According to Harris and Keady [12] a person's self worth and place in society is built up around their occupation, therefore if they retire early or lose jobs often it could have detrimental effects on their own wellbeing. Tindall and Manthorpe [11] suggest possible workshops n day centres to fulfil the need for meaningful activities to mimic work and therefore improve self worth.

The need for access to information about benefits and employment rights is important due to being entitled to many benefits [2], this is briefly mentioned in a large number of my articles but not enough detail, and it is overlooked and dwarfed by the importance of staying in employment.

## Sexual and family Relationship issues

People living with early onset dementia may have active sexual relationships with partners; also people with EOD may have dependants and younger families which the disease could have a more profound effect on so relationships either sexual or within a family is very important. According to Tindall and Manthorpe [11] the stigma of mental health means that families can feel isolated and embarrassed about the resent diagnosis of dementia, from this the assumption could be made that if a person is embarrassed they could possibly not seek help which



then could cause stress and anxiety within their relationship. Due to the change in the relationship help is needed such as counselling which could help to relive distress within the family (early onset dementias). In Bentham and La Fontaine [9] it states that family therapy could also be a solution for problems caused within the family. Another issue that arises from dementia is performing the families'roles [12] which also fit into the life course theory and normalisation theory explained previously in this article. There is also the pressure of possible generic links within the family, according to Bentham and la Fontaine [9] it suggests that liaisons and family counselling could help with the complications that can arise though possible inherited disorders. It is important to also consider that friendships are lost through the difficulty of coping and caring for someone with early onset dementia so the feeling of isolation exacerbated [12].

Children are very vulnerable therefore diversely affected by people living with dementia such as feeling scared and confused by the changing personality traits and deterioration of the condition [11]. According to Vliet et al. [10] children especially adolescence came into conflict with the person living with dementia due to misunderstanding and aggravation. In Tindall and Manthorpe [11] it also mentions that the persons living with dementia may have parents that are alive, the difficulty for the parents to see their child living with this condition is an important consideration.

Maintaining sexual relationships can be an issue, in Harris and Keady [12] it states that people living with dementia find it hard to be attractive when it is so hard to conduct simple everyday tasks, this puts pressure on a person's self worth and relationships with their partner. Another problem within sexual relationships is that people are reluctant to ask for support which is needed when the symptom of dementia start to rise [12]. A common difficulty is that as the condition progresses the person with dementia forgets their partner [6], this poses the question of what also they might forget for example sexuality, it is stated in Harris and Keady [12] that this is a fairly researched area and a subject of its own. Another issue that arises from developing early onset dementia is that the person generally loses empathy and finds it hard to socially interact [10] this could cause problems in relationships due to possibly not responding to help when needed as stated in Vliet et al. [10].

It is also mentioned the needs of carers and families that care for people with dementia, due to the difficulties this portrays people commonly suffer from depression and anxiety [9]. This issue shows that there is a need for respite care but if as mentioned previously there is a lack of age appropriate services there seems to be a conflict of interest of the service users needs verses the carer's needs.

### **A multidisciplinary approach and expertise in early onset dementia care**

The need for multi disciplinary and inter disciplinary action is important in early onset dementia according to Ferran et al.

[5] it allows accurate diagnosis of dementia and identifies it from similar conditions. It was also stated in a National Health Service Health Advisory Service report in 1997 the need for a multi disciplinary approach [13].

Chaston [8] a multi disciplinary team helps to hasten the diagnosis and the access to after care for people living with early onset dementia. As mentioned earlier in the review an early diagnosis is vital in early onset dementia to make the condition easier for the person involved, their families and carers [4]. Another view held is that a broader multi disciplinary approach should be used to explore the experience of a person living with early onset dementia which would help to develop a collaborative approach to assist in supporting someone through the diagnosis period [9] a possible question that could be asked is that if a multi disciplinary team was to undertake the diagnosis and support a person through the diagnosis would a lot of the issues relating to GP's inability to correctly diagnoses early onset dementia be solved.

In [8] it states that there is a need for a care pathway for people living with early onset dementia, it is also mentioned that there is an overall lack of awareness and training to create a successful pathway for this condition. The Alzheimer's society and Dementia North have campaigned to make a clear pathway to support people with early onset dementia, it has also been noted that due to a person living with early onset having unique needs a multi disciplinary team would be the most successful. The need for clinical leaders and multi disciplinary approaches are vital in early onset dementia, in Bentham and la Fontaine [9] it states that there is the need for strong clinical leadership within well motivated and specialist teams that have reserved clinical call time.

There is a need for expertise in early onset dementia to offer better support people living with the condition for example according to Bentham and La Fontaine [5] in frontal temporal dementia there is a need for the knowledge of the biochemical and cognitive psychopathology of the condition. In Ferran et al. [5] it states that there is the need for more regional and sub regional expertises to coordinate and supplement pre existing services. According to Bentham and la Fontaine [9] people with early onset dementia require a skilled multi disciplinary team to help with the needs of a person living with dementia especially delivering psychosocial interventions which fits in with using counselling and group therapy to help with someone's self worth image as detailed previously in this study. In Beattie et al. [6] its states that services should be multi disciplinary and as such address the needs of the individual and not the category of people, this echoes the debate of age appropriate services verses need appropriate services detailed previously in this review.

### **Recommendations**

According to [4,6,12] there is a major lack of research and literature in early onset dementia this is possibly due to the low prevalence of early onset dementia compared to late onset

dementia. From my findings the need for faster diagnosis in early onset dementia has been stated and to reform the way diagnosis are conducted [3,4,6-9, 11,12].

There is also the need for a more successful multi disciplinary teams to work successfully within early onset dementia [3-9,11]. It is also a general consensus that most services for people with early onset dementia and their families is fairly inadequate especially as mentioned earlier in age appropriate services [12]. The study has also highlighted the need for more research to be done about early onset dementia especially according to Tindall and Manthorpe [11]. In the views of children in families that have a member living with early onset dementia. Another suggestion is that more studies compare age appropriate services verses need assessed services [4].

In Tindall and Manthorpe (11) it states that research has to collaborate with the medical field, it also mentions about communication between people with early onset dementia, their families and carers and health professionals such as nurses and social workers..

There is also possibly the need for reflection on the role of a GP in the diagnosis of early onset dementia through the consensus that diagnosis is not given sensitively enough [6,8,9] It is also noted that the opinion and voice of the person with early onset dementia is important in future literature and research [8]. According to Barber [13] current practices should be evaluated and through the survey the hope is that change may follow to help with the service provision for people living with early onset dementia.

## Conclusion

In this study there have many themes discussed in detail which show how the needs of people living with early onset dementia can be met. Age appropriate services is an issue that is common in the literature, it argues the need for age appropriate services verses need appropriate services. Accurate and timely diagnosis is also important due it possibly allowing people to cope with their condition more successfully and access services earlier [10]. due to people living with early onset dementia commonly being in working age employment and financial issues are profound so support is need to help with this need [4] Relationships are an important factor to consider in early onset dementia due to people being younger and possibly

having families and partners .The last theme discussed in detail is the need for multi disciplinary approach and expertise in dementia care; this has explored previously fits into most of the other themes and helps to meet the needs stated such as multi disciplinary approaches reducing diagnosis time [5].

This survey has noted many unique need that represent them self in early onset dementia, it is widely accepted that there is a shortfall in services and support in this emerging and needy group of individuals [4,8-10,12] and through the identification of the need for further research one can only hope that thing may improve and influence change for the better in caring for people with early onset dementia.

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