

## G.3 Care planning, review and co-ordination

### G.3.1 Health and social care co-ordination

#### Review questions

- What are the most effective methods of care planning, focussing upon improving outcomes for people with dementia and their carers?
- How should health and social care be co-ordinated for people living with dementia?

#### G.3.1.1 CERQual tables

#### Themes identified for the self-management intervention for people living with dementia and their carers

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: The program training was enjoyable							
1 (Faith 2015)	Focus groups, interviews	Although people living with dementia said that they could not recall all of the activities, they had enjoyed the program.	Serious <sup>1</sup>	High	High	Moderate <sup>3</sup>	Low
Theme: The participants felt empowered							
2 (Faith 2015, Moore 2011)	Focus groups, interviews	The training program encouraged people living with dementia to continue with their hobbies and goals (Faith 2015). Access to a budget provided a sense of empowerment (Moore 2011).	Serious <sup>1</sup>	High	High	High	Moderate
Theme: Caregivers felt burdened and people living with dementia felt disempowered							
1 (Toms 2015)	Semi-structured interviews	The caregivers felt responsible and burdened. This left the person with dementia feeling disempowered.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: Support groups were considered valuable							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Toms 2015)	Semi-structured interviews	Peer support, such as support groups, was considered valuable by participants.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: Caregivers and people with dementia questioned what would happen once time-limited support ended							
1 (Toms 2015)	Semi-structured interviews	Additional support, such as a support group, was available, but these were often time-limited, which led both caregivers and people with dementia to the question of what happened when such support ended.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: There was a lack of support							
1 (Toms 2015)	Semi-structured interviews	People living with dementia and their caregivers felt that there was a lack of support.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: Respondents thought that professional support was important for effective self-management							
1 (Toms 2015)	Semi-structured interviews	Respondents thought that professional support was important for effective self-management, and valued this resource. They thought that this help was necessary because not everything could be self-managed within the family.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: Many respondents were unsure how to access the services and reported finding them limited and poorly integrated							
1 (Toms 2015)	Semi-structured interviews	Many respondents were unsure how to access the services that were available, and reported finding them limited and poorly integrated. This made it harder to self-manage the condition.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: Some people living with dementia used practical aids to support their memory							
1 (Toms 2015)	Semi-structured interviews	Some people living with dementia used practical aids to support their memory.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: What was most pertinent to carers was the diminished ability of the person living with dementia to complete daily tasks							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Toms 2015)	Semi-structured interviews	What was most pertinent to carers was the diminished ability of the person living with dementia to complete daily tasks.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: The approach of normalising difficulties was evident in many interviews							
1 (Toms 2015)	Semi-structured interviews	The approach of normalising difficulties was evident in many interviews.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: People living with dementia and their carers endured hardship without showing their feelings or complaining							
1 (Toms 2015)	Semi-structured interviews	A sense of stoicism, often expressed when respondents gave their ideas about self-management, was evident in many interviews, and this seemed to be a form of psychological management.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: People with dementia were uncertain about the future. This led to lack of confidence and a diminished belief that they could self-manage							
1 (Toms 2015)	Semi-structured interviews	Some people with dementia discussed losing confidence. It was implied that this loss of confidence could diminish people's belief that they could self-manage. In some cases, this loss of confidence seemed to relate to uncertainty about the future and how the illness would progress	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Low
Theme: Diaphragmatic breathing was relaxing							
1 (Faith 2015)	Focus groups, semi-structured interviews	Participants found the relaxation activity of diaphragmatic breathing relaxing	Serious <sup>1</sup>	High	High	Moderate <sup>3</sup>	Low
Theme: Funding for respite was useful for carers							
1 (Moore 2011)	Interviews	Funding for respite was useful for carers	Serious <sup>1</sup>	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Very low
Theme: Finding personal assistants was difficult							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Moore 2011)	Interviews	Finding suitable individuals to become personal assistants was difficult for some people	Serious <sup>1</sup>	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Very low
Theme: When suitable individuals became personal assistants, there were positive results							
1 (Moore 2011)	Interviews	When suitable individuals became personal assistants, there were positive results	Serious <sup>1</sup>	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Very low
<ol style="list-style-type: none"> <li>1. Theme only identified in studies at high risk of bias.</li> <li>2. This theme conflicts with another. The difference may be partially, although not completely explained by the fact that participants in Moore 2011 had access to a budget and those in Toms 2015 did not.</li> <li>3. Only a limited amount of evidence to support this finding.</li> </ol>							

#### Themes identified for outcome-focussed/needs-led care vs standard care

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: Standard care: Familial carers often feel not able to cope							
1 (Gethin-Jones 2014)	Semi-structured interviews	The most common concern of familial carers is the feeling of not being able to cope	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Standard care: Carers felt isolated							
1 (Gethin-Jones 2014)	Semi-structured interviews	The sense of isolation expressed by the participants came over very strongly. This isolation appeared to come from their sense that they were on the outside with little control because the care was planned by the other professionals. Family carers felt that they were isolated as they had all the responsibility and in their eyes and potentially all the blame when things went wrong.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Outcome-focussed care: Carers' self-reported well-being improved after the outcome-focused intervention had been implemented							
2 (Gethin-Jones 2014,	Semi-structured interviews	There was an improvement in the carers' self-reported subjective well-being, after the outcome-focused homecare intervention had been implemented.	Not serious	High	High	High	High

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Rothera 2008)							
Theme: Outcome-focussed care: Carers felt the subjective well-being of their relative had improved after the outcome-focused care intervention							
1 (Gethin-Jones 2014)	Semi-structured interviews	All the carers felt the subjective well-being of their relative had improved after the six month outcome-focused care intervention.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
1. Only a limited amount of evidence to support this finding.							

### Themes identified for community-based case management

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: Meeting health and social care professionals at home was more relaxing and less stressful							
1 (Gibson 2007)	Interviews	Meeting health and social care professionals at home was more relaxing and less stressful compared to using the memory service.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Being at home facilitated communication							
1 (Gibson 2007)	Interviews	Being at home facilitated communication with health and social care professionals.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: The case manager was good at identifying needs and providing the right support							
1 (Iliffe 2014)	Interviews	The case manager was good at identifying needs and providing the right support.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Carers expected case managers to provide information about dementia and services							
1 (Iliffe 2014)	Interviews	Carers expected case managers to provide information about dementia and services.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Case managers should be proactive in asking carers and people living with dementia if they feel they need assistance							
1 (Iliffe 2014)	Interviews	Case managers should be proactive in asking carers and people living with dementia if they feel they need assistance. This is because participants frequently expressed a reluctance to initiate contact with the case	Not serious	High	High	Moderate <sup>1</sup>	Moderate

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		manager, which undermines the concept that they could ask for help when needed.					
Theme: A common reason why people living with dementia and their carers do not initiate contact with case managers is because they do not associate case managers with assisting with day-to-day issues							
1 (Iliffe 2014)	Interviews	A common reason why people living with dementia and their carers do not initiate contact with case managers is because they associate case managers with assisting with 'major' problems such as arranging residential care homes. They do not associate case managers with assisting with day-to-day issues.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: People living with dementia and their carers preferred to have their case manager based at their GP's surgery							
1 (Iliffe 2014)	Interviews	People living with dementia and their carers preferred to have their case manager based at their GP's surgery. This is because there was the perception that their GP's surgery would then be a 'one-stop shop'. In addition, having the case manager at the GP's surgery provided an additional opportunity to talk to the case manager while visiting the GP's surgery.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Appointments at clinics were more anxiety provoking compared to home appointments							
1 (Gibson 2007)	Interviews	For some, exposure to others at more severe stages of the illness within the clinic was a potent contributor towards anxiety, illustrating what could be expected as the disease progresses. Appointments at home removed this exposure.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Nurses as case managers were perceived as providing a more direct link to the GP for advice and support							
1 (Iliffe 2014)	Interviews	From the perspectives of some people living with dementia and their carers, nurses as case managers were perceived as providing a more direct link to the GP for advice and support for comorbidities and minor ailments.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>1</sup>	Low
Theme: A direct link to the GP was not a priority because they preferred their case manager to have expertise in social services							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Ilfie 2014)	Interviews	From the perspectives of some people living with dementia and their carers, a direct link to the GP was not a priority because they preferred their case manager to have expertise in social services. The inference is that they would prefer a social worker to be the case manager.	Not serious	High	Moderate <sup>2</sup>	Moderate <sup>1</sup>	Low
Theme: People living with dementia and their carers emphasised interpersonal skills							
1 (Ilfie 2014)	Interviews	People living with dementia and their carers emphasised interpersonal skills such as empathy.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Case management made access to services easier							
1 (Ilfie 2014)	Interviews	Case management made access to services easier including GPs, benefit checks and links to other services.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Case managers should respond as quickly as possible to questions							
1 (Ilfie 2014)	Interviews	Case managers should respond as quickly as possible to questions from people living with dementia or their carers.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: The idea of background support was valued by people living with dementia and their carers							
1 (Ilfie 2014)	Interviews	A key aspect of case management valued by people living with dementia and their carers was the idea of background support that could easily be called on at a time of need.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: There needed to be time and opportunities to develop a deeper relationship.							
1 (Ilfie 2014)	Interviews	For people living with dementia and their carers to feel comfortable about contacting the case manager in the event of difficulties, there needed to be time and opportunities to develop a deeper relationship.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Face-to-face contact was preferred							
1 (Ilfie 2014)	Interviews	Face-to-face and telephone contact were both considered acceptable, although face-to-face contact	Not serious	High	High	Moderate <sup>1</sup>	Moderate

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		was often preferred as it facilitated relationship building better than telephone contact.					
Theme: Some people living with dementia and their carers do not mind contact by telephone							
1 (Iliffe 2014)	Interviews	Some people living with dementia and their carers appreciate the service that case managers provide and also appreciate how hard they work. Therefore, they do not mind contact by telephone.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Case managers should explain what support they can provide							
1 (Iliffe 2014)	Interviews	Case managers should explain to carers, and where appropriate to people living with dementia, what support they can provide.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Participants found case management more useful than dementia advisors							
1 (Iliffe 2014)	Interviews	Participants found case management more useful than dementia advisors. This is because case management offers continuity of care but dementia advisors do not.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
<ol style="list-style-type: none"> <li>1. Only a limited amount of evidence to support this finding.</li> <li>2. This finding conflicts with another. Among people living with dementia and their carers, opinion is divided.</li> </ol>							

### Themes identified for memory-clinic case management

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: The memory service was well received							
1 (Hean 2011)	Interviews	The memory service was well received.	Very serious <sup>1,2</sup>	High	High	Moderate <sup>3</sup>	Very low
Theme: People living with dementia experienced an increase in their quality of life							
1 (Sonola 2013)	Focus groups, survey	People living with dementia generally experienced an increase in their quality of life.	Serious <sup>2</sup>	High	High	Moderate <sup>3</sup>	Low
Theme: Familial carers' stress scores improved or remained stable							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Sonola 2013)	Focus groups, survey	Familial carers' stress scores improved or remained stable for all the carers measured.	Serious <sup>2</sup>	High	High	Moderate <sup>3</sup>	Low
Theme: There was difficulty and effort in accessing treatment							
1 (Gibson 2007)	Interviews	There was difficulty and effort in accessing treatment	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: For memory services that do not have post-diagnostic support, participants expressed feelings of abandonment							
1 (Kelly 2016)	Semi-structured interviews	For memory services that do not have post-diagnostic support, many participants expressed feelings of abandonment or 'being sent away' by professionals on receipt of diagnosis.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: For memory services that do have post-diagnostic support, participants explained the value of having support as soon after diagnosis as possible							
1 (Kelly 2016)	Semi-structured interviews	For memory services that do have post-diagnostic support, people with dementia and their carers explained the value of having support as soon after diagnosis as possible and the importance of skilled, knowledgeable, sensitive project workers to deliver support.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: Carers frequently reported positively on the help received from the project workers with claiming benefits							
1 (Kelly 2016)	Semi-structured interviews	Carers frequently reported positively on the help received from the project workers with claiming benefits.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: Carers spoke of receiving support with arranging Power of Attorney							
1 (Kelly 2016)	Semi-structured interviews	Carers spoke of receiving support with arranging Power of Attorney and valued the input from project workers in negotiating the process.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: Participants found the information they received useful							
1 (Kelly 2016)	Semi-structured interviews	Family members and one person newly diagnosed with dementia found the information they received (books and leaflets) along with general advice useful.	Not serious	High	High	Moderate <sup>3</sup>	Moderate

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: Exposure to others at more severe stages of the illness within the clinic was a potent contributor towards anxiety							
1 (Gibson 2007)	Interviews	For some, exposure to others at more severe stages of the illness within the clinic was a potent contributor towards anxiety, illustrating what could be expected as the disease progresses. Appointments at home removed this exposure.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: The coordination of care was valued							
2 (Hean 2011, Sonola 2013)	Interviews, focus groups, survey	The coordination of care was valued.	Not serious	High	High	High	High
Theme: The service made carers and people living with dementia feel supported and reassured							
2 (Hean 2011, Sonola 2013)	Interviews, focus groups, survey	The service and nature of the staff made carers and people living with dementia feel supported and reassured. (Having a named person to contact in times of crisis, and the security that they would not left to manage alone.)	Not serious	High	High	High	High
Theme: The language used was not quite right							
1 (Hean 2011)	Interviews	The language used was not quite right.	Very serious <sup>1,2</sup>	High	High	Moderate <sup>3</sup>	Very low
Theme: People living with dementia felt pressure of time because the psychiatrist was busy							
1 (Hean 2011)	Interviews	People living with dementia felt pressure of time because the psychiatrist was busy.	Very serious <sup>1,2</sup>	High	High	Moderate <sup>3</sup>	Very low
Theme: Some found it difficult to get to the right people and get the answers needed							
1 (Hean 2011)	Interviews	Some found it difficult to get to the right people and get the answers needed.	Very serious <sup>1,2</sup>	High	High	Moderate <sup>3</sup>	Very low
Theme: There were accounts of receiving insufficient information							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Kelly 2016)	Semi-structured interviews	There were accounts of receiving no information, or insufficient or inappropriate information following diagnosis.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: Some carers expressed discomfort with some of the information they received							
1 (Kelly 2016)	Semi-structured interviews	Some carers expressed discomfort with some of the information they received. Some felt that it was too much to face too soon. Many participants stated that a 'one size fits all' approach was not what they wanted.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: Participants valued information that was delivered on a one-to-one basis and targeted to individual needs and wishes							
1 (Kelly 2016)	Semi-structured interviews	Participants valued that information was delivered by the project workers on a one-to-one basis and specifically targeted to individual needs and wishes.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: People living with dementia and their carers liked seeing the same person throughout treatment							
2 (Hean 2011, Willis 2011)	Interviews, semi-structured interviews	People living with dementia and their carers liked seeing the same person throughout treatment.	Not serious	High	High	High	High
Theme: People living with dementia and their carers recognised the one stop shop aspect of the memory service.							
1 (Willis 2011)	Semi-structured interviews	Convenience. People living with dementia and their carers recognised the one stop shop aspect of the memory service. Ten participants described the memory service as a central point of access to all necessary services.	Serious <sup>2</sup>	High	High	Moderate <sup>3</sup>	Low
Theme: People living with dementia and their carers thought that home visits were very good							
1 (Hean 2011)	Interviews	People living with dementia and their carers thought that home visits were very good.	Very serious <sup>1,2</sup>	High	High	Moderate <sup>3</sup>	Very low
Theme: People living with dementia and their carers valued transport that was arranged by case managers/project workers.							
1 (Kelly 2016)	Semi-structured interviews	People living with dementia and their carers valued transport that was arranged by case managers/project workers.	Not serious	High	High	Moderate <sup>3</sup>	High

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: Care management does not promote advance care planning							
1 (Kelly 2016)	Semi-structured interviews	Care management does not promote advance care planning.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
Theme: Memory service post-diagnostic support when individualised and one-to-one, causes people with dementia to re-engage							
1 (Kelly 2016)	Semi-structured interviews	Memory service post-diagnostic support when individualised and one-to-one, causes people with dementia to re-engage socially or with old hobbies.	Not serious	High	High	Moderate <sup>3</sup>	Moderate
<ol style="list-style-type: none"> <li>1. Method of recruitment not mentioned. Recruitment numbers not clarified.</li> <li>2. Theme only identified in studies at high risk of bias.</li> <li>3. Only a limited amount of evidence to support this finding.</li> </ol>							

### Themes identified for Daisy Chain: a commercial person-centred dementia service that seems to have some elements of case management

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: The person-centred community-based dementia service was well received							
1 (Gladman 2007)	Observation and semi-structured interviews	The person-centred community-based dementia service was well received.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
Theme: The person-centred community-based dementia service provides a personalised service							
1 (Gladman 2007)	Observation and semi-structured interviews	The person-centred community-based dementia service provides a personalised service.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
Theme: The person-centred community-based dementia service helped carers to cope							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Gladman 2007)	Observation and semi-structured interviews	The person-centred community-based dementia service helped carers to cope.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
Theme: The person-centred community-based dementia service kept the people living with dementia and their accommodation clean							
1 (Gladman 2007)	Observation and semi-structured interviews	The person-centred community-based dementia service kept the people living with dementia and their accommodation clean.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
Theme: The person-centred community-based dementia service enabled people living with dementia to stay at home							
1 (Gladman 2007)	Observation and semi-structured interviews	The person-centred community-based dementia service enabled people living with dementia to stay at home.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
Theme: The person-centred community-based dementia service had good communication							
1 (Gladman 2007)	Observation and semi-structured interviews	The person-centred community-based dementia service had good communication.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
Theme: There is a 'right time' for someone living with dementia to move to a residential care home							
1 (Gladman 2007)	Observation and semi-structured interviews	There is a 'right time' for someone living with dementia to move to a residential care home.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
Theme: Some carers would prefer the person living with dementia to remain in their own home							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Gladman 2007)	Observation and semi-structured interviews	Some carers would prefer the person living with dementia to remain in their own home.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
Theme: There are sometimes differences of opinion							
1 (Gladman 2007)	Observation and semi-structured interviews	There are sometimes differences of opinion between people living with dementia, paid carers and familial carers.	Not serious	Moderate <sup>1</sup>	High	Moderate <sup>2</sup>	Low
<ol style="list-style-type: none"> <li>1. Full details of what is contained in the intervention are unclear.</li> <li>2. Only a limited amount of evidence to support this finding.</li> </ol>							

### Themes identified for non-specified case management style(s) in predominantly remote and rural areas in Scotland

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: Carers said they required more help							
1 (Innes 2014)	Semi-structured interviews	Carers generally expressed satisfaction with support received but said they required more help	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
Theme: The lack of alternative options sometimes led to provision of no support at all							
1 (Innes 2014)	Semi-structured interviews	The lack of alternative options sometimes led to provision of no support at all.	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
Theme: Poor coordination of services							
1 (Gorska 2013, Innes 2014)	Semi-structured interviews	Poor coordination of services. The participants particularly emphasized poor communication between existing services, which results in unsatisfactory case management and delays in service provision. The need	Not serious	High	High	High	High

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		for a single point of access to information and service coordination was expressed as a means to manage these challenges and to facilitate more efficient and effective service delivery. Participant reports also highlighted inconsistencies in care provision and suggested the need for well-defined care pathways.					
Theme: Some experienced lack of continuity of care							
1 (Gorska 2013, Innes 2014)	Semi-structured interviews	Some experienced lack of continuity of care. This can lead to poor communication and is confusing.	Not serious	High	High	High	High
Theme: Lack of mental stimulation							
1 (Gorska 2013)	Semi-structured interviews	Lack of mental stimulation.	Not serious	High	High	Low <sup>2</sup>	Low
Theme: Some people living with dementia do not want to make use of day centres							
1 (Innes 2014)	Semi-structured interviews	Some people living with dementia do not want to make use of day centres.	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
Theme: Some GPs have a specific interest in dementia and this improves communication							
1 (Innes 2014)	Semi-structured interviews	One interviewee pointed out that some GPs have a specific interest in dementia and this improves communication.	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
Theme: There were high satisfaction levels with the support received from the Community Mental Health Team							
1 (Innes 2014)	Semi-structured interviews	There were high satisfaction levels with the support received from the Community Mental Health Team.	Serious <sup>1</sup>	High	High	High	Moderate
Theme: Participants discussed the importance of staff building a rapport with the person with dementia							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Innes 2014)	Semi-structured interviews	Participants discussed the importance of staff building a rapport with the person with dementia. This facilitates communication.	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
Theme: When it was available, a carers' group was appreciated							
1 (Innes 2014)	Semi-structured interviews	When it was available, a carers' group (caregiver support) was appreciated.	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
Theme: Practical support was important to carers who received help from services regularly							
1 (Innes 2014)	Semi-structured interviews	Practical support was important to most carers who received help from private or voluntary services regularly. Carers perceived this type of support as an opportunity to take a respite from caregiving responsibilities. Many used the respite time to rest, run errands which required getting out, or to attend carers meetings.	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
Theme: Other sources of post-diagnostic support were from family, friends, and neighbours							
1 (Innes 2014)	Semi-structured interviews	Other sources of post-diagnostic support were from family, friends, and neighbours.	Serious <sup>1</sup>	High	High	High	Moderate
Theme: Some carers have difficulty leaving their relative with someone else							
1 (Innes 2014)	Semi-structured interviews	Some carers have difficulty leaving their relative with someone else.	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
Theme: Information was not always in a format appropriate for the person with dementia or carers							
1 (Innes 2014)	Semi-structured interviews	Information was not always in a format appropriate for the person with dementia or carers.	Serious <sup>1</sup>	High	High	High	Moderate
Theme: Participants preferred a direct approach when receiving information with the opportunity to ask questions							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Innes 2014)	Semi-structured interviews	The way information was delivered was important. Participants preferred a direct approach with the opportunity to ask questions.	Serious <sup>1</sup>	High	High	High	Moderate
Theme: Care managers should be proactive in anticipating the needs of people living with dementia and their carers							
1 (Innes 2014)	Semi-structured interviews	Care managers should be proactive in anticipating the needs of people living with dementia and their carers and provide relevant information.	Serious <sup>1</sup>	High	High	Low <sup>2</sup>	Very low
<ol style="list-style-type: none"> <li>1. Methods of recruitment are not described.</li> <li>2. Very limited amount of evidence to support this finding.</li> </ol>							

#### Themes identified for case management in residential care homes

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Theme: The need for activities, interaction and outings was the most prevalent theme overall							
1 (Popham 2012)	Focus groups, interviews	The need for activities, interaction and outings was the most prevalent theme overall.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Participants valued freedom to carry out normal everyday activities and domestic chores							
1 (Popham 2012)	Focus groups, interviews	Participants spoke about having the freedom to be able to carry out normal everyday activities and domestic chores.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
Theme: Rooms with views were highly valued							
1 (Popham 2012)	Focus groups, interviews	Rooms with views were highly valued.	Not serious	High	High	Moderate <sup>1</sup>	Moderate
<ol style="list-style-type: none"> <li>1. Only a limited amount of evidence to support this finding.</li> </ol>							

### Case planning – the Adaption-Coping Model

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Family carers also valued having the opportunity to learn more about dementia and see other people in the same situation.							
1 (Brooker 2017)	Focus group interviews	It enabled some carers to gain a broader perspective on their own experiences, and facilitate adjustment. By seeing how their relatives were treated at the Meeting Centre and responded to the interactions, some carers were able to reflect on the difficulties faced in their everyday lives.	Serious <sup>1</sup>	High	High	High	Moderate
Participants liked the warmth and friendliness of the staff							
1 (Brooker 2017)	Focus group interviews	Participants liked the warmth and friendliness of the staff. It gave them confidence.	Serious <sup>1</sup>	High	High	High	Moderate
The Meeting Centre provides a supportive space for feelings to be aired							
1 (Brooker 2017)	Focus group interviews	Some carers felt that they were unable to share their true feelings or experiences with family members for fear of judgement, and again the Meeting Centre provides a supportive space for those feelings to be aired	Serious <sup>1</sup>	High	High	High	Moderate
The experience enabled some people to reflect upon their own emotional adjustment							
1 (Brooker 2017)	Focus group interviews	The experience enabled some people to reflect upon their own emotional adjustment	Serious <sup>1</sup>	High	High	High	Moderate
The planned activity provided a useful structure							
1 (Brooker 2017)	Focus group interviews	The planned activity provided a useful structure	Serious <sup>1</sup>	High	High	High	Moderate
The participants felt that they were not alone							
1 (Brooker 2017)	Focus group interviews	The participants felt that they were not alone	Serious <sup>1</sup>	High	High	High	Moderate
Carers were able to get a different perspective							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Brooker 2017)	Focus group interviews	Seeing other people in similar situations and getting outside perceptions helped one carer to reassess how he views his wife's situation	Serious <sup>1</sup>	High	High	High	Moderate
Attendance was good							
1 (Brooker 2017)	Focus group interviews	The participants enjoyed attending and therefore the attendance was good	Serious <sup>1</sup>	High	High	High	Moderate
1. Theme only identified in one study at moderate risk of bias							

### Case planning – Rotherham Carers Resilience Service

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Carer – Often people suggested that they felt unsure and extremely anxious about the person they were caring for							
1 Dayson (2016)	Interviews	Often people suggested that they felt unsure and extremely anxious about the person they were caring for	Serious <sup>1</sup>	High	High	High	Moderate
Carer – Carers felt that the service provided them with a great deal of reassurance, both in practical terms but also emotional							
1 Dayson (2016)	Interviews	Carers felt that the service provided them with a great deal of reassurance, both in practical terms but also emotional	Serious <sup>1</sup>	High	High	High	Moderate
Carer – The relief people felt moving forwards							
1 Dayson (2016)	Interviews	Understanding that the situation will change in the future, beneficiaries of the service described how their knowledge of the service helped them to feel more positive about the future	Serious <sup>1</sup>	High	High	High	Moderate
Carer – Participants felt supported							
1 Dayson (2016)	Interviews	People now felt 'in the system', and felt reassured knowing where they could go for support should anything occur in the future.	Serious <sup>1</sup>	High	High	High	Moderate
Carer – Carers reported that the knowledge and experience of the staff was key							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 Dayson (2016)	Interviews	Carers were reassured by the expertise of the staff.	Serious <sup>1</sup>	High	High	High	Moderate
Carer – Carers found that they had benefited from the information provided							
1 Dayson (2016)	Interviews	This is because they had learnt something new or had been reassured that what they were experiencing was not an isolated case	Serious <sup>1</sup>	High	High	High	Moderate
Carer – Carers received practical assistance							
1 Dayson (2016)	Interviews	Examples of help ranged from assessments of homes, recommending alarms and safety devices, through to benefits advice and information about community transport and the provision of a home based support service, whereby a care support worker can come to sit with someone for support and reassurance whilst their carer/partner is away	Serious <sup>1</sup>	High	High	High	Moderate
1. Theme only identified in one study at moderate risk of bias							

### Coordination – for people living with dementia who have comorbidity

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Family members were often proactive in facilitating continuity and negotiating access to services for their relatives with dementia.							
1 Bunn (2017)	Semi-structured interviews	This included acting as an advocate for their family member with dementia, noticing when something was wrong and seeking help	Serious <sup>1</sup>	High	High	High	Moderate
Family members were often proactive in helping clinicians make treatment decisions, such as whether to thrombolysate a PLWD after a stroke.							
1 Bunn (2017)	Semi-structured interviews	Family carers also had a significant role in coordinating their relative's care, navigating healthcare systems and facilitating continuity of care; for example, managing appointments, organising transport, keeping records of test results and medication	Serious <sup>1</sup>	High	High	High	Moderate
Family members were often proactive in actively transferring information between HCPs and different services							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 Bunn (2017)	Semi-structured interviews	Family members were often proactive in actively transferring information between HCPs and different services	Serious <sup>1</sup>	High	High	High	Moderate
The availability of a family carer to act as a proxy, and provide consent, information and post-discharge support impacted on a PLWD's access to care.							
1 Bunn (2017)	Semi-structured interviews	HCPs recognised that PLWD who lived alone, or did not have support from a family carer or advocate, were particularly vulnerable and may have poorer access to care	Serious <sup>1</sup>	High	High	High	Moderate
Although HCPs in our study valued the role family carers played, there was little formal recognition of the carers' role, and no systems for negotiating how or when carers' views could be incorporated into care planning.							
1 Bunn (2017)	Semi-structured interviews	This was reflected in the many examples provided by their interviews where carers felt undervalued or excluded from decision-making about their relative's care.	Serious <sup>1</sup>	High	High	High	Moderate
There were many challenges for family carers.							
1 Bunn (2017)	Semi-structured interviews	These included difficulty in understanding how health systems worked and who to contact, their own health problems, emotional and practical challenges of changing roles	Serious <sup>1</sup>	High	High	High	Moderate
Living at a distance and/or with work and family commitments that made taking on responsibilities for day-to-day care difficult.							
1 Bunn (2017)	Semi-structured interviews	Caring at a distance may be particularly problematic for carers of PLWD as it is difficult for them to offer support or to monitor adherence to medication over the phone.	Serious <sup>1</sup>	High	High	High	Moderate
Support from social networks, such as extended family, friends and religious groups, and from third sector providers were clearly important to PLWD and their carers.							
1 Bunn (2017)	Semi-structured interviews	Support from social networks, such as extended family, friends and religious groups, and from third sector providers were clearly important to PLWD and their carers.	Serious <sup>1</sup>	High	High	High	Moderate
Formal support from health and social care was often seen as inadequate.							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 Bunn (2017)	Semi-structured interviews	Formal support from health and social care was often seen as inadequate.	Serious <sup>1</sup>	High	High	High	Moderate
PLWD and family carers valued continuity, in terms of relationships with practitioners but also in terms of encounters that factored in the impact of dementia, that built on earlier conversations and appointments and that included people with dementia and their carers in decision-making.							
1 Bunn (2017)	Semi-structured interviews	Many PLWD and carers reported positive relationships with their GPs and recognised the role that GPs played in coordinating care.	Serious <sup>1</sup>	High	High	High	Moderate
How PLWD managed their care, for example, either independently, in tandem with a family carer or with external health and social care support, was linked to where they were on the dementia trajectory.							
1 Bunn (2017)	Semi-structured interviews	Some people with early stage dementia were still able to self-manage their care. As the dementia got worse, the PLWD's ability to self-manage declined and responsibility moved, either partly or totally, from the PLWD to a carer. These transitions often happened when strategies to facilitate self-management, for example, memory aids, diaries and dosette boxes, ceased to be effective	Serious <sup>1</sup>	High	High	High	Moderate
Current infrastructure did not support the sharing of information across different specialities.							
1 Bunn (2017)	Semi-structured interviews	Current infrastructure did not support the sharing of information across different specialities.	Serious <sup>1</sup>	High	High	High	Moderate
For many participants, their comorbid health condition predated the diagnosis of dementia.							
1 Bunn (2017)	Semi-structured interviews	Despite this, there appeared to be inadequate consideration by some services of the implications of a diagnosis of dementia on the management of existing conditions.	Serious <sup>1</sup>	High	High	High	Moderate
1. Theme only identified in one study at moderate risk of bias							