
COMMUNICATING: DIAGNOSES & CONSULTATIONS FOR PEOPLE WITH DEMENTIA

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Disclaimer: This document is a general guide, to be followed subject to the clinician's judgment and person's preference, choices and decisions in each individual case. The guideline is designed to provide information to assist decision making and is based on the best evidence available at the time of development of this publication.

1. Key Messages

Communicating the diagnosis

- A person-centred approach, considering language, culture, education and other factors, should be adopted.
- The diagnosis or the possibility of dementia should be communicated unless disclosure cannot be understood by the person or is against the person's expressed wishes. This respects the person's autonomy.
- Communication of the diagnosis or possibility of dementia should be timely. Timeliness is determined by assessing readiness and risk.
- Communication of the diagnosis or possibility of dementia should occur over time when appropriate.
- Whilst the autonomy of the person with dementia is a primary consideration, carers/family members should be present, whenever possible, during conversations about a dementia diagnosis.
- The person and their carer need support and information about the diagnosis. Implications of the condition and plans for subsequent consultations should be discussed with the person.

Communicating with the person and carer

- The desire to communicate is usually retained and should be optimised.
- Respectful and effective verbal and non-verbal communication is needed to enhance understanding of the person, their dementia, their preferences/choices, and to optimise involvement in decision-making.
- Communicate directly with the person with dementia and, if present, secondarily with their carer(s)/family members.

2. Practice Points – What Can I Do?

a) Timely communication of the diagnosis

Preparation

- Raise the possibility of dementia as a diagnosis and establish the person's consent for investigation and preferences for diagnosis disclosure.¹ Explain that knowledge of their condition will help the person to understand their health, seek appropriate assistance/further opinions and access dementia specific services.² Where the person's family request the diagnosis not be disclosed, this conflict should be resolved through discussion which addresses their disclosure concerns (e.g. evoking fear, distress or catastrophic reaction).³⁻⁵
- Use knowledge of the person with dementia and their family to plan a timely, individualised and appropriate approach to diagnostic investigation and diagnosis communication.¹ Consider the person's wishes, awareness, capacity to understand, psychological and social resources and safety, including the risk of negative psychological reactions.^{4, 6-8}

Assessing each person's capacity to understand the diagnosis

- Early in the investigative phase of the diagnosis, determine the person's and carer's understanding and attitudes about cognitive loss and dementia.^{1, 4, 9} Address any misconceptions or myths about the condition.⁹

After performing the cognitive function test say "I cannot exclude Alzheimer's disease or dementia from the results of this test, so we will need to do some more testing. Do you have any questions?"
(Suggestion from the GP Forum)

- Employ methods such as the 'ask-tell-ask' method¹⁰ to explore the person's knowledge and understanding of memory testing and dementia. Ask "Do you have any questions about the memory testing we have done/would like to do?" Followed by "I am concerned that you may have dementia. Have you heard of this condition?" and "Do you have any questions about what dementia is?"

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- Recognise and respect that the person with dementia and their carer/family may need time to comprehend and understand the implications of a diagnosis of dementia. Approaching the diagnosis over time can be helpful (e.g. by initially raising the condition as a possibility and later moving to more certainty).

I do think that there is sometimes an issue communicating with a person with early cognitive problems – especially if they are educated and articulate – where they respond with very plausible phrases to cover up their difficulties **(GP Informant)**.

- Plan person-specific diagnosis support and information before meeting with the person to disclose their diagnosis. Resources, including for people from culturally and linguistically diverse backgrounds, can be accessed from the national Dementia Australia website (<https://www.dementia.org.au/>).
- Should a person with dementia prefer not to be told the diagnosis, respect this preference.⁹ The diagnosis may also be withheld if the person is unable to comprehend the diagnosis.^{5, 11} However, it is imperative that the person and carers understand there is a problem involving cognition/thinking that may need medical investigations and management.⁹

Communicating the diagnosis:

- Plan sufficient time to communicate the diagnosis and for the person to ask questions. Some people ask many questions, others may not.⁹ A longer appointment is preferable, avoiding interruptions and distractions (e.g. phone calls).^{1, 9, 12}
- Ensure that the carer/family members are present when the diagnosis of dementia is communicated to the person.^{4, 9, 13} Each situation needs to be considered in the context of the patient, knowledge of their relationship with the carer/family and their expressed wishes. Where circumstances prevent a carer from being present, the GP needs to judge how and when to disclose the diagnosis.
- Signal to the person that you need to discuss some bad news.

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- People with dementia should be addressed as partners in the conversation, as with any other person.¹²
 - Tailor communication to the preferences, needs, and ideas of the person with dementia, and include information on prognosis as well as diagnosis.^{1, 13} The ask-tell-ask method helps to tailor diagnosis disclosure.¹⁰ This method involves asking the person what they want to know and what they do know, telling them some limited information, then asking what they understand by what you just said. The diagnosis and prognosis may need to be revisited on many occasions, particularly if the GP or nurse has long term care of the patient.
 - Use inclusive, appropriate and non-stigmatising language. When communicating with the person and carers/family members about BPSD use the terms ‘changed behaviours’ and ‘expression of unmet needs’ rather than BPSD, behaviours of concern, challenging or difficult behaviours, wanderer or wetter (see the Dementia Australia Language Guidelines <https://www.dementia.org.au/resources/dementia-language-guidelines>).¹⁴
 - Communicate a specific diagnosis rather than a vague reference to memory or cognitive problems. The word ‘dementia’ should be used in the diagnosis, or/and more specific dementia terminology when known (e.g. Alzheimer’s disease).⁹
 - Explain dementia as a condition of the brain so the person with dementia understands the physical cause for cognitive problems and changes in behaviour.¹²
 - Impart information needed to make initial sense of the diagnosis. Identify immediate practical implications of the diagnosis however delay non-urgent discussion and decisions until subsequent consultations – this allows the person with dementia and the carer time to absorb the information.^{1, 4} Emphasise the often slow progression of the condition, the availability of symptomatic treatments and, although not successful at this time, ongoing research looking to find cures.³

You prepare people that this may be bad news. You set up the appointment. You make sure that their significant other is with you, and with them, and you give them the bad news. And you say, “and I want to see you tomorrow – or I want to see you next week”. “I want to see you in three days’ time – to talk about all the ways forward from here”. “Here’s some information – just take it away and look at it”. But I don’t expect them to take in anything more at that moment. That is not the moment... they need to go away and cry. They need to go away and be with their family and they will come back with a thousand questions. But right then, it is not much point in giving them information.

(Suggestion from the GP Forum)

- Reassure the person that there will be opportunities to discuss the diagnosis again ^{1, 4} during ongoing GP consultation throughout the course of their dementia.⁹ Agree on follow-up plans.
- If helpful at the time of diagnosis disclosure, refer to support services (e.g. Dementia Australia’s “Living with Memory Loss” program).¹⁵
- The GP should ensure the patient is reviewed within 2 months of the specialist consultation at which the diagnosis is made, to assist the be scheduled after a specialist diagnosis is made, to further assist the person and carer in understanding the condition, the implications of the diagnosis, and care options.⁴

Responding to emotional reactions:

- Allow the person with dementia time to process receiving their diagnosis.⁶
- Acknowledge the person’s emotional response and that of the carer as appropriate (e.g. anger, denial, shock, fear or relief).^{4, 16}
- Respond to the person empathetically. Provide a balance of hope, by emphasising preserved abilities and skills, and realism in line with the person’s individuality.¹³
- Explore coping strategies that may assist the person with dementia come to terms with the diagnosis.^{1, 4, 9}

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- Encourage maintenance of social activities and other secondary prevention approaches, such as the Mediterranean diet, exercise and social activities (see Dementia Prevention).¹⁷
 - Plan for, assess and address potential negative psychological consequences of disclosure (e.g. minimisation, anger, denial, shock, grief, depression, suicidal ideation).⁴ Provide information, explanation and support for the person with dementia and their carer throughout the diagnostic process.^{3, 4} Counselling may also be offered under a mental health care plan if the person is in the community and has depression, anxiety or other psychological condition as well as dementia, or otherwise referral to a psychogeriatrician.

Subsequent consultations

- Plan ongoing conversations with the person.⁴ Focus on abilities rather than disabilities and secondary prevention (see chapter on dementia prevention). In the following 2-3 consultations cover:
 - dementia signs and symptoms;
 - course and prognosis of dementia;
 - treatments and strategies for health promotion/wellbeing;
 - resources for financial and legal advice, advocacy and support; and
 - medico-legal issues, including driving and planning for the future.³
- Provide written information on practical and emotional support; negotiate a GP management plan.¹ Reconsider the management of other chronic disease that will be affected by dementia and may need renegotiating as part of the plan.
- Plan and/or utilise opportunistic conversations with carers/family to assess coping and communicate information and resource contact details (e.g. support groups, adult day care and respite care).⁹ Advise and encourage use of Dementia Australia associations and resources.¹⁴
- Consider providing a written summary of discussions for later reference.¹⁸

b) Communicating with the person

- Establish a person-centred relationship that optimises the person’s ability to communicate, participate in decision-making and understand their condition.^{19, 20}
- Respond to the communication needs of CALD people by using a range of strategies to enhance communication, including professional interpreters.³
- Use a non-threatening, face-to-face position.²¹⁻²³
- Maintain comfortable eye contact.²¹⁻²³
- Keep introductions simple i.e. just one or two sentences. This will help the person with dementia focus on the conversation itself.^{12, 19, 21, 24}
- Focus on one question or idea at a time.^{12, 19, 21, 24}
- Speak in short simple sentences of four to six words with one verb per sentence and using the active voice.^{12, 19, 21, 24}
- Wait for a response, pause between ideas and/or signal topic changes to allow for slowed cognitive processing (e.g. Can we talk about your medications now?).^{12, 19, 21, 24}
- Encourage responsiveness by displaying patience, speaking in a soft audible tone and using rephrasing, repetition and further explanation of ideas,²⁰ especially if English is the second language.
- Match intonation with message (e.g. if asking a question, make it sound like a question).^{12, 19, 21, 24}
- Use hand and facial gestures to reinforce verbal messages.²¹⁻²³
- Be aware of mood and emotion.²⁴
- Avoid confusing terms, such as ‘positive’ and ‘negative’ results. Focus on the main issues and regularly check that the information provided is being understood by the person with dementia.¹²
- Avoid metaphors, colloquialisms and pronouns. Poor working memory inhibits the ability to co-reference e.g. “Your husband told me...He said...”.^{12, 19, 21, 24}

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- Search for specific information by asking who, where, when questions. Clarify information using questions requiring a yes/no response.²⁴ However remain aware that people with dementia frequently answer 'yes' when they are uncertain of the correct response.²⁴
 - As appropriate, employ communication strategies used by the carer.²³
 - When cognition is no longer able to support an answer, family members may need to act as primary informants.²⁴

c) Communicating with the carer

- Be aware that the carer may be stressed during consultations because of the need to observe and support the person they are caring for, as well as talking to the GP. Provide clarifications, reassurance and written summaries (if possible).
- Involve the patient in the decision-making processes during conversations with the carer. Ensure the patient is not ignored.¹⁹
- Ask the carer to describe how they communicate with the person in different contexts and for different functions.^{21, 23}

d) Supporting carer communication with the person who has dementia

- Advise carers of resources to assist them with caring, including the Dementia Australia's 'Communication' Fact Sheet (<https://www.dementia.org.au/resources/help-sheets>).²⁵
- Suggest communications strategies that optimise communication, including:
 - attracting the person's attention (e.g. use the person's name, position yourself at the other person's eye level and keep eye contact);
 - avoiding distraction (e.g. turn off the radio or television, move to a quieter place);
 - having one person talk at a time;
 - being aware of their own expression and body language – show interest, try to appear relaxed and calm;

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- simplifying communication (e.g. short direct sentences using familiar words; avoid pronouns like 'she' or 'he' or 'it');
 - using visual aids (e.g. gestures, actions; show objects or pictures) while being aware that interpretation of visual information may also be impaired;
 - listening carefully, watching the person's non-verbal cues, expressions or direction of gaze to get their message;
 - encouraging communication using familiar and interesting topics (e.g. memorabilia, photos);
 - avoiding arguments if the person seems confused. Acknowledge the person's feelings and try to gently move on to another topic;
 - providing enough time to allow the person to respond – wait for 5 seconds after speaking before expecting a response;
 - helping the person find the right word by: suggesting a word; repeating an unfinished sentence with a suitable word; ask 'Do you mean...?';
 - repeat, then rephrase if necessary (i.e. if he/she does not understand what was said try repeating your sentence and, if not successful, say the sentence in a different way);
 - providing reminders of the topic of the conversation (e.g. clearly mention the topic of your conversation; repeat the topic throughout the conversation); and
 - making it clear when you are changing the topics of the conversation by pausing between topics, or by mentioning the topic change.²⁰
- Identify ways to avoid conversational embarrassment for the person with dementia (e.g. suggesting it is better to repeat a small part of what a patient has just said, and add further information, than simply correcting the person).²⁶

3. Literature Review

a) Communicating the diagnosis

There has been considerable controversy as to whether a diagnosis of dementia should be communicated, and if so, when and how.⁷ The literature notes multiple factors which interplay and influence disclosure of diagnosis including:

- person's preferences;
- capacity;
- the psychological and social resources available;
- person's insight into their impairment;
- certainty of the diagnosis;
- fears about causing psychological harm including depression or suicide, and
- wishes of relatives not to inform the person with dementia.^{1, 4, 6, 7}

Although some controversy continues, research suggests a significant number of people express the wish to know if they had dementia.^{11, 27-31} In a GP waiting room survey of patients aged 50 years and over who did not have dementia, 66.2% responded that they would like to know if they had Alzheimer's Disease.³¹ Moreover, the majority of people referred to memory services were keen to know their diagnosis and the long-term consequences.^{27, 28} For example, Elson found 86% wanted to know the cause of their memory difficulties, with 69% offering a variety of reasons for wishing to know if diagnosed with Alzheimer's disease (e.g. to seek out support at Dementia Associations; to know what was wrong; and so that family would understand their behaviour).²⁷ However, this may be a biased sample because those who don't want to know would be unlikely to seek memory clinic referral.

A systematic review addressing the subjective experiences of people with dementia has found that people with dementia can get relief from diagnosis, even though it may come with some measure of shock or fear. Participants noted that communication of the diagnosis was frequently communicated to their relatives and spouses, rather than to them, and they identified their preference for inclusion, as an "adult and accountable person", in the diagnostic process.^{16(p38)}

In addition to personal preference, there is agreement that the person with dementia has the right to know their diagnosis.^{4-6, 11} Communicating the diagnosis to the person respects the person's autonomy and enables participation in care to the degree their cognitive functioning allows.⁶ Furthermore, evidence from a cross-sectional study has suggested awareness of the diagnosis of dementia is associated with a higher quality of life.³²

Knowledge of their diagnosis may help the person to:

- confirm their suspicions and gain a better understanding;
- participate in and maximise the opportunity for future care planning and getting their affairs in order whilst able (e.g. financial planning, assigning power of attorney);
- obtain a second opinion;
- maximise treatment possibilities including psychological and pharmacological therapy; and
- plan and facilitate access to support services.^{5, 11, 29}

In addition, disclosure of the diagnosis enables:

- the issue of driving to be discussed;
- the person with dementia to share anxieties with carer(s);
- the person to move into management, focusing on abilities rather than disabilities, and engage in activities that may slow progression of the condition^{5, 11, 29}; and
- access to dementia services, relevant information and dementia medication.³³

It is also possible that the carer/family members may wish to know the diagnosis, in order to understand the issues they are dealing with. Whenever possible and appropriate, the carer should be present when the person with dementia is told.^{4, 9, 13} When there are circumstances in general practice that prevent carer/family being present, the GP will need to judge how and when to tell the carer.

Whilst there is agreement that the diagnosis of dementia should be communicated^{4, 6, 11}, it is important to consider whether non-disclosure is supported in particular circumstances. Importantly, the one argument for non-disclosure which has retained

support over time is when respecting the right of the person with dementia not to know their diagnosis.⁵

Debates about non-disclosure of a dementia diagnosis that are no longer supported include when doctors have concerns that the person may experience negative consequences.⁵ Some have feared that disclosure will reduce hope and result in distress or depression.^{5, 6, 11} Others fear suicidal ideation and/or the precipitation of suicide.⁴⁻⁶ However, few adverse psychological consequences have been reported from diagnosis disclosure,^{1, 6, 11} including the precipitation of suicide.^{4, 5} Rather, reactions to diagnosis disclosure, such as anger, denial, shock, sorrow and grief, are normal coping reactions to a life-altering diagnosis and should be anticipated and addressed as part of a planned and ongoing disclosure process.^{4, 6, 11} Patients with adequate individualised support cope with diagnosis disclosure and, over time, negative reactions are outweighed by gains from the positive aspects of disclosure described above.^{1, 6}

Uncertainty of the diagnosis has also been given as a reason for withholding a dementia diagnosis.⁵ However, with increasing clarity in diagnostic criteria, a lack of absolute certainty is no longer considered a reason not to explain the known clinical picture to the patient.^{4, 5} During diagnosis disclosure, areas of diagnosis uncertainty should be discussed.⁴

The person's inability to understand their diagnosis, due to a lack of insight or the degree of their cognitive impairment, has also been raised as a reason for non-disclosure.^{4, 5, 29} Whilst each person's situation varies, disclosure is supported in the earlier stages of dementia when the positive aspects of knowing benefit the person.⁵

Timely communication of the diagnosis

Dementia Australia (formerly Alzheimer's Australia) and other organisations call for timely diagnosis and timely communication of that diagnosis. This implies a person-centred approach that is tailored to individual preferences.^{28, 34} Making a diagnosis of dementia is both a medical process and a social act – an act that puts the person with dementia into a new and highly stigmatised social group.³⁴ Communication of the diagnosis should respect the individuality of the person, gauge the receptiveness of the person with dementia to a dementia diagnosis, and provide information appropriate to the stage of disease progression. Moreover, some people with

dementia only want to know there is an underlying cause of their memory problems, though don't want to be diagnosed with Alzheimer's disease ³⁵ – hence, the need for sensitivity in communicating the diagnosis.

Timeliness in the diagnosis of dementia does not refer to simple chronological notions of time.⁸ Dhedhi and colleagues' narrative analysis of GPs' accounts of encounters with patients with suspected dementia revealed a timely diagnosis was a cumulative process, with importance placed on the correct or opportune time, with timeliness very different from early diagnosis.⁸ In this process, GPs caring for people with early dementia needed to consider multiple questions including the immediate situation, safety, consent, autonomy, appropriate access to services, and planning for the future, to enable a nuanced judgement that encompassed helping the person ⁸ “to the right extent, at the right time, with the right aim, and in the right way”.^{36(p403)}

It is important to be conscious of the terms used when discussing dementia.

Dementia Australia has developed Language Guidelines

(<https://www.dementia.org.au/resources/dementia-language-guidelines>) to promote inclusive, appropriate and non-stigmatising language associated with dementia.¹⁴

These guidelines and other resources may be accessed from the national Dementia Australia website (<https://www.dementia.org.au/>).

The cultural background of a person with dementia can influence interpretation of language used when discussing dementia – in some cultures, dementia may be regarded as a mental illness, in others it may be understood as a normal part of aging. Dementia Australia's report on perceptions of dementia and the words and phrases used across different ethnic communities,³⁷ along with other culturally and linguistically diverse resources, may be accessed from the national Dementia Australia website (<https://www.dementia.org.au/>).

How to communicate the diagnosis

Communication of a dementia diagnosis equates to the breaking of bad news and therefore requires honesty whilst also being cognisant of and sensitive to capabilities and needs of the person with dementia, though this is often accompanied with concern to avoid harm.³⁸ GPs should ascertain what experience and knowledge the person with dementia and their carer have about cognitive loss and dementia,^{1, 4, 9} so that any misconceptions or myths can be addressed. Doing so can help the GP tailor

communication and learn of the person with dementia/carer's ability to deal with this information, taking into account beliefs, preferences, family tensions, racial and ethnic differences. People's preferences differ, with some not wanting to know, some wanting to know a little, and some wanting to know everything.⁹ The GP needs to discuss with carers the stage the person is currently at, what issues are anticipated over the next six months, and which resources may be helpful.^{1, 4, 9}

Recent evidence suggests communicating the diagnosis should be an ongoing process rather than a one-off event.^{11, 13} For example, the findings from one study reinforced the need to progressively disclose a diagnosis to enable both the person with dementia and their carer to prepare, and highlighted the importance of providing detail about dementia and its progression, as well as emphasising hope during discussions.¹³ Therefore, the communication process should involve the following steps.

Preparation

- Raise the possibility of dementia as a diagnosis, establishing the person's preferences for diagnosis disclosure, and plan the approach to communicate the diagnosis.^{1, 3}
- Consider knowledge of the person with dementia and their family to inform the most appropriate way to communicate the diagnosis.¹
- A person's preference to not to be told the diagnosis, should be honoured.⁹
- Whilst the autonomy of the person with dementia is a primary consideration, ensure that a family member is present whenever possible.^{4, 9, 13}
- Establish and reveal patient information to the carer(s) in accordance with the wishes of the person with dementia.⁴

Assessing the person's capacity to understand their diagnosis

- Even when the person does not want the diagnosis revealed, it is imperative that he/she and their carers understand there is a problem – a problem that may need medical investigations and management.⁹
- Determine the person and their carer's understanding of, and attitude to, dementia, during early diagnostic investigations.^{1, 4, 9} This may allow the gradual introduction of the possibility of a diagnosis of dementia.^{1, 9}

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- Implications of the diagnosis should be considered and discussed. For example, someone functioning in a leadership role must confront when and how to step down, or alternatives to driving oneself should be discussed.⁹
 - It is important for the GP to address any misconceptions or myths.⁹

Communicating the diagnosis

- Communication should be tailored to the preferences, needs, and ideas of the person with dementia and include the provision of information on prognosis as well as diagnosis.^{1, 13}
- The person with dementia should be addressed as a partner in the conversation, as with any other patient.¹²
- An explanation that “dementia is an illness of the brain” might be useful. This can help the person with dementia’s understanding about cognitive problems and changes in behaviour having a physical cause.¹²
- Check if the person has any questions and provide time for clarifications.^{1, 4}
- It is recommended that a specific diagnosis should be communicated – the word dementia should be used in the diagnosis, or Alzheimer’s disease, if appropriate.⁹
- A longer initial appointment is preferable if possible, avoiding interruptions and distractions (e.g. phone calls).^{1, 9, 12}
- The GP should emphasise to the person with dementia and their family that sharing the diagnosis is the beginning of an ongoing conversation, and they will have the opportunity for ongoing GP consultation throughout the course of dementia.⁹
- Referral to support services such as the Dementia Australia’s “Living with Memory Loss” program is appropriate at this stage (<https://www.dementia.org.au/support/services-and-programs/services-and-programs/living-with-memory-loss>).
- A follow-up appointment with the GP may be helpful following a specialist diagnosis, to further assist in understanding the condition and its implications.⁴

Responding to emotional reactions

- Allow time for the person with dementia to process receiving their diagnosis.⁶
- Assess the immediate psychological impact of the diagnosis and address negative psychological consequences (e.g. anger, denial, shock, grief, suicidal ideation, depression) throughout the process of diagnosis by providing the person and carer with education and support.⁴
- Where the person with dementia reacts with denial to their diagnosis, the GP should respond by reflecting or naming the emotion (e.g. ‘You cannot believe this is happening to you?’) rather than trying to convince the person with arguments.¹²
- Similarly, it may be helpful to reassure the person that “You are still a person, even if you have dementia”. This goes to a deeper belief in loss of personhood associated with loss of cognitive capacity.³⁹

Focusing on quality of life and well-being

- Foster a realistic sense of hope by, where possible, discussing and acknowledging preserved abilities and daily function.^{1, 4, 9}
- Encourage maintenance of social activities.^{1, 9}
- Explore coping strategies that help the person with dementia come to terms with the diagnosis.^{1, 4, 9}
- Display empathy and provide a balance of hope and realism in line with the person’s individuality.¹³

Support when discussing the diagnosis

Ensure that carer(s) are present for support if possible, during consultations.¹³

Follow-up plans for the person with dementia and their carer(s) should be made and discussed when giving the diagnosis.^{4, 13} However, when planning for the future, recognise that decisions may need to be made across multiple meetings – this allows the person with dementia and their carer time to absorb the information.¹

Providing support necessitates identifying the practical implications of the diagnosis and should include arrangements for referral and follow-up. This could include clarifying follow-up arrangements; discussing issues such as driving, preventative and health promotion activities, and available support services; providing written

information on practical and emotional support; and negotiating a management plan.¹ Encourage linkage to Dementia Australia and other sources of additional resources such as support groups, adult day care and respite care.⁹ Additionally, Mastwyk and colleagues found the majority of memory clinic patients and carers they interviewed wanted a written summary of their feedback information which they could refer to later.¹⁸ Overall, it is critical to take a positive approach to treatment emphasising the value of lifestyle changes, other psychosocial interventions, medication and the provision of continued support.^{9, 11, 13, 34}

More information on services and support can be found in specific chapters – see Continuing Care, Younger Onset Dementia and Carer Support as appropriate.

b) Enhancing communication

Dementia can profoundly affect a person's ability to communicate as the person loses the ability to use and understand language.^{20, 21, 24} The changes in the brain that occur with progression of dementia often impact on the person's memory, and communication difficulties may subsequently arise.⁴⁰ Systems within memory function can be affected in quite different ways:

- Episodic memory (remembering new events and information) can be an area of progressive impairment.²⁰
- Semantic memory (understanding what objects are, recognising people, and understanding language) is usually less affected, or affected at a later stage.²⁰
- Word-finding, auditory understanding, and conversation skills can be affected at different times during progression.^{20, 21}
- Spatial awareness and activities of daily living deficits tend to be progressive.⁴⁰

Most people with mild-moderate dementia appear to show preservation of non-declarative (or implicit) memory processes (e.g. procedural learning such as skills and habits which do not require conscious recollection of information, such as drying dishes or smelling a rose).²⁰

Because of difficulties with word-finding or dysphasia, people with dementia may have difficulty communicating their needs verbally.²¹ As a result, they may exhibit agitation, wandering or other behaviours as a way of communicating a need.^{20, 21} In addition, the person may have difficulty in following rapid or complex speech;

encoding or decoding meaning or conveying meaning in a logical way. Moreover, people with dementia can be particularly susceptible to misinterpreting communication due to misreading non-verbal communication. For example, they may misread body language or have impaired ability to understand facial expressions. They may not be able to filter out environmental distractions such as television, radio or loud sounds.^{20, 23, 41} As dementia progresses, the person's attention may wander, they may speak off topic, repeat ideas, lack coherence and engage less in conversations.²⁰ Moreover, people with dementia frequently answer 'yes' when they are uncertain of the correct answer.²⁴ A significant barrier to communication can be the language spoken, as older people from CALD backgrounds frequently speak only the language they grew up with, having lost any English language skills they had acquired.⁴²

Despite these changes, the desire to communicate is retained in most people with dementia. Finding a respectful way to communicate with the person may increase their sense of competence and improve the quality of the interaction for both parties.²⁰ If you know the person well, some brief reminiscences about past times may provide this respectful communication and reinforce rapport.

Optimising communication when a person has dementia

Effective communication incorporates use of a wide range of listening and verbal skills such as structuring and signposting the consultation, use of appropriate language, reinforcing and repeating information.¹ Non-verbal communication is also important in facilitating comprehension (e.g. facial expressions, direction and intensity of gaze, facing the person when speaking to them, hand gestures).^{22, 23} Significantly, a person with dementia's non-verbal expression and understanding may be better than their verbal communication.²⁰ If a carer is available, talk to them to learn how they communicate with the patient and if they have particular suggestions.^{20, 21}

Effective non-verbal strategies include using a non-threatening, face-to face positioning and sitting at the same level.⁴³ Maintaining eye contact can be reassuring to people who are having trouble understanding intention or speech, while using gestures (e.g. point, show) may facilitate comprehension.²¹⁻²³ Weirather notes that although understanding of language deteriorates with dementia, comprehension of emotion and mood are still present, and are likely to have more effect on the person

with dementia than the words themselves. Therefore, GPs should be aware of the mood they convey as well as the information they give.²⁴

The GP may find they need to encourage verbal participation by the person with dementia during in their consultation.²⁰ Effective verbal strategies include keeping introductions short to move quickly to the main focus of the conversation, and slowing speech by pausing between ideas to avoid overload and allow for slowed cognitive processing (though there is no need to talk slowly).¹² Furthermore, one question should be asked at a time and wait for a response (the person with dementia may need more time to respond – do not interrupt or be impatient with slowness); discuss only one idea at a time; and use intonation to make your intent clear (e.g. if asking a question, make it sound like a question). Metaphors and colloquialisms should be avoided, along with pronouns as poor working memory inhibits the ability to co-reference, e.g. “Your husband told me...He said...”. Additionally, it is preferable to speak in short simple sentences of four to six words with one verb per sentence using the active voice.^{12, 19, 21, 24} Rephrasing, repetition and further explanation of ideas, patience and speaking in a soft, though audible, tone may also encourage responsiveness in people with dementia.²⁰

Weirather²⁴ suggests searching for specific information using “Wh” questions (e.g. what, who, where, when), though notes that ‘why’ and ‘how’ questions may pose some difficulty. These may be followed by yes/no questions, although when cognition is no longer able to support an answer, family members may have to act as primary informants.²⁴ Clinicians should be mindful of confusing statements, such as ‘positive’ and ‘negative’ results, focus on the main issues and check if and how information is understood.¹²

Communication support strategies for the patient’s carer

Smith et al. noted that non-verbal abilities may be preserved, and that people with dementia want to communicate.²⁰ They recommend the following set of strategies, which can be used by carers, to optimise communication between them and the person with dementia:

- attract the person’s attention (e.g. use the person’s name, position yourself at the other person’s eye level and keep eye contact);
- avoid distraction (e.g. turn off the radio or television, move to a quieter place);

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- have one person talk at a time;
 - monitor expression and body language – show interest, try to appear relaxed and calm;
 - keep it simple (e.g. short direct sentences using familiar words; avoid pronouns like ‘she’ or ‘he’ or ‘it’);
 - use visual aids (e.g. gestures, actions; show objects or pictures) while being aware that interpretation of visual information may also be impaired;
 - listen carefully, watching the person’s non-verbal cues, expressions or direction of gaze to get their message;
 - encourage and engage in communication using familiar and interesting topics (e.g. memorabilia, photos); and
 - don’t ask test questions or argue if the person seems confused – acknowledge the person’s feelings and try to gently move on to another topic.²⁰

A GP might also suggest, to a carer, ways to avoid conversational embarrassment for the person with dementia. For instance, it is better to repeat a small part of what a patient has just said, and add further information, rather than to simply correct the person.²⁶

Other practical communication strategies that the carer could use include:

- providing enough time to allow the person to respond – wait for 5 seconds after speaking before expecting a response;
- helping the person find the right word by: suggesting a word; repeating an unfinished sentence with a suitable word; ask ‘Do you mean...?’;
- repeat, then rephrase if necessary (i.e. if he/she does not understand what was said try repeating your sentence and, if not successful, say the sentence in a different way);
- providing reminders of the topic of the conversation (e.g. clearly mention the topic of your conversation; repeat the topic throughout the conversation);
- making it clear when changing the topic of the conversation by leaving time between topics or by mentioning a topic change.²⁰

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Appendix 1 – Extract from NHMRC Guidelines

The following recommendations and evidence strength/quality definitions have been extracted from [Clinical Practice Guidelines and Principles of Care for People with Dementia](#).

3

Recommendations

Communicating the diagnosis

Number	Detailed Recommendation
45 PP	The diagnosis of dementia should be communicated to the person with dementia by a medical practitioner.
46 PP	The medical practitioner should be honest and respectful and use a gradual and individualised approach when communicating the diagnosis to the person with dementia and their carer(s) and family.
47 PP	The medical practitioner should recognise that people have the right to know their diagnosis and the right not to know their diagnosis. In rare cases where the person with dementia indicates that they do not wish to be told his or her diagnosis, this wish should be respected. The medical practitioner should ensure that carer(s) and family are supported to manage this situation and that the consequences of this decision are managed (e.g., driving). Conflicts, such as when the carer(s) and family request the diagnosis not be communicated to the person with dementia should be resolved by further discussions over time if necessary.
48 PP	The medical practitioner should provide information about dementia in a clear manner and emphasise that progression is often slow, symptomatic treatments are available and that research is striving to find cures, though so far without success.
49 PP	Medical practitioners should be aware that people with a history of depression and/or self-harm may be at particular risk of depression, self-harm or suicide following a diagnosis of dementia, particularly in the first few months post diagnosis. While such reactions are believed to be uncommon, counselling should be offered as an additional way to support the person during this time.

3(p1X)

Information and support for the person with dementia

Number	Detailed Recommendation
50 PP	Health and aged care professionals should be aware that people with dementia, their carer(s) and family members may need ongoing support to cope with the difficulties presented by the diagnosis.
51 CBR	<p>Following a diagnosis of dementia, health and aged care professionals should, unless the person with dementia clearly indicates to the contrary, provide them and their carer(s) and family with written and verbal information in an accessible format about:</p> <ul style="list-style-type: none"> • the signs and symptoms of dementia • the course and prognosis of the condition • treatments • sources of financial and legal advice, and advocacy • medico-legal issues, including driving.
52 EBR <i>Very low</i>	People with a diagnosis of dementia, particularly those living alone, should be provided with information about how to join a social support group.
53 PP	Health and aged care professionals should ensure that the person with dementia and his or her carer(s) and family are provided with written and verbal information regarding appropriate services available in the community (including those offered by Alzheimer's Australia, Carers Australia, Aged Care Assessment Teams and My Aged Care). Any advice and information given should be recorded.

3(pX)

Communication Principles

Number	Detailed Recommendation
3 PP	Health and aged care professionals should use language that is consistent with the Dementia Language Guidelines and the "Talk to me" good communication guide for talking to people with dementia.
15 PP	Health and aged care services working to improve the health and care of Indigenous Australians living with dementia should be culturally sensitive and informed and utilise translators and/or cultural interpreters where necessary, particularly during assessment, when communicating the diagnosis and gaining consent.
17 PP	Health and aged care professionals should consult with family and Indigenous community representatives when developing a culturally appropriate care plan. A case manager (who may be an Indigenous community-based staff member) can assist with accessing and coordinating services required and advocating for the person with dementia.
20 PP	Health and aged care services need to recognise and be responsive to the cultural and linguistic needs of CALD people living with dementia, their carer(s) and families. Services should utilise a range of communication tools, including working with bilingual bicultural staff or professional interpreters across the whole service pathway, particularly during assessment, when communicating the diagnosis and gaining consent.

3(pV-VII)

Definitions of types of recommendations

Evidence-based recommendation (EBR) - Recommendation formulated after a systematic review of the evidence, with supporting references provided.

Consensus based recommendation (CBR) - Recommendation formulated in the absence of quality evidence, when a systematic review of the evidence has failed to identify any quality studies meeting the inclusion criteria for that clinical question.

Practice point (PP) - A recommendation that is outside the scope of the search strategy for the systematic evidence review and is based on expert opinion.

Definitions of GRADE ratings of the quality of the evidence

High - Further research is very unlikely to change our confidence in the estimate of effect.

Moderate - Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.

Low - Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.

Very Low - Any estimate of effect is very uncertain.^{3(pp.IV)3(pp.IV)}

Appendix 2 – Evidence summary for chapter

Evidence summary for literature reviews (communicating the diagnosis)

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Bamford et al (2004) UK	Systematic review of empirical data regarding diagnostic disclosure of dementia	Studies (n=59; 1985-2003) included 34 from search of five electronic databases (Medline, Embase, Web of Science, CINAHL, Sociological Abstracts) and 25 by manual searches. Methodological issues of included studies were outlined: convenience samples, few evaluated representativeness of participants; low response rates, information on response rates not always provided – three studies systematically analysed non-response; one-third of studies that used standardized questionnaires or interviews described pilot work; there was risk of bias in several studies – interviews with people with dementia or their carer were conducted by a practitioner involved in the care provision.	Studies included or excluded using inclusion criteria: English language and original empirical data about disclosure.	NA	Existing evidence regarding diagnostic disclosure in dementia was inconsistent and limited; many of the studies had methodological shortcomings; beliefs and attitudes to diagnostic disclosure and reported practice varied widely suggesting a significant discrepancy between current practice and guidance about disclosure ; studies of the impact of disclosure indicated both negative and positive consequences of disclosure for people with dementia and their carers; the perspectives of people with dementia appeared largely neglected.	1.Y 2.Y 3.Y 4.Y 5.Y 6.Y 7.Y 8.Y 9.Y 10.CA 11.N

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Cornett & Hall (2008) USA	Non-systematic review about issues in disclosing a diagnosis of dementia and factors to consider when disclosing the diagnosis.	NA (38 refs)	NA	NA	Issues discussed: capacity, awareness/insight, autonomy, doing no harm, and truth telling. In conclusion, the authors offered their view that the advantages of disclosing a dementia diagnosis to a patient outweighed the disadvantages. Disclosure does not need to occur in one session, tailor to the patient – some may benefit from gradual disclosure over a few sessions. The process should be individualised and consider the patient's cognitive and emotional state, their specific needs and desires, along with consideration to the needs of the carer.	1.NA 2.NA 3.CA 4.CA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.N
Fisk et al. (2007) Canada	Non-systematic review on disclosure of the diagnosis of dementia	NA. Recommendations re disclosure approved at the Third Canadian Consensus Conference on Dementia (CCCD) (1999) listed. Studies from PubMed and Embase databases.	Preference given to publications between 1996 – 2006.	NA	Recommended a progressive disclosure process addressing: remaining diagnostic uncertainty, treatment options, future plans, financial planning and legal issues (e.g., assigning power of attorney), driving issues, available support services; assessment of the potential for adverse psychological consequences to disclosure and provision of education and support to the patient and their carer(s) throughout the disclosure process	1.NA 2.NA 3.CA 4.CA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.Y

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Grossberg et al. (2010) USA	Non-systematic review supporting expert opinion to develop a set of recommendations for GPs on how best to communicate with patients and carers about the diagnosis and management of AD.	NA. Expert opinion (n=6) supported by academic literature from PubMed database.	Expert opinion (moderated dialogue aimed at generating consensus opinion; only statements endorsed by all authors included). Search limits English language, 1996–2008; search terms: Alzheimer's disease, primary care, diagnosis, management, caregiver, family, patient-physician relationship.	NA	Recommended: timely diagnosis and initiation of therapy for AD to optimise treatment response and opportunity for future planning; tailor how a diagnosis of AD is disclosed to the individual and their family; communicate a specific diagnosis and include carers as possible; focus on the positive aspects of the patient's current capabilities and the value of maintaining function. With progression of the dementia, focus toward managing behaviours and accommodating functional decline; communicate with carers about these issues and to recommend resources for management.	1.NA 2.NA 3.CA 4.CA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.Y

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Pinner & Bouman (2002) UK	Non-systematic review on how disclosure of the diagnosis relates to the field of dementia.	NA	NA	NA	Disclosure of a diagnosis of dementia occurs less frequently than with other illnesses (e.g. cancer); inconsistencies exist between physician reports of their usual practice and their views on potential benefits and patient's wishes. Most carers appear to prefer the diagnosis to be withheld from the patient; most practitioners and carers would wish to know if they had dementia; elderly peer group studies showed most would wish to be fully informed. Truthful disclosure is advocated with when and how to disclose to be explored in partnership with the patient.	1.NA 2.NA 3.CA 4.CA 5.NA 6.NA 7.NA 8.CA 9.NA 10.NA 11.N
Raicher & Caramelli (2008) Brazil	Non-systematic literature review about disclosure in dementia and truth telling, especially in Alzheimer's disease (AD).	NA	NA	NA	Disclosure of AD diagnosis is not a common practice among physicians, although the discussion on diagnostic disclosure can be valuable for improving the care of AD patients and their families.	1. Y 2.NA 3.CA 4.Y 5.NA 6.NA 7.NA 8.NA 9.NA 10.NA 11.N

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Robinson et al. (2011) UK	Systematic review on the patient and carer experiences in the transition to dementia	Updated Bamford et al., 2004 above. Studies returned as per search strategy for Bamford et al. (2004) with the inclusion of additional terms specific to Mild Cognitive Impairment (MCI). Studies supplemented by hand search of reference lists of articles retrieved and consultation with experts in the field (n=62).	Studies published in 2003 which had been included by Bamford et al. (2004) were excluded. Inclusion criteria: English language and original empirical data addressing disclosure of a diagnosis of dementia or MCI.	NA	Still a dearth of empirical research about how a diagnosis of dementia is disclosed; most people with dementia wish to know the diagnosis; 'Alzheimer's' appears to have a more negative connotation than 'dementia'; key challenges for the person with dementia were coming to terms with losses on multiple levels; most people with dementia do not appear to experience long-term negative effects on their psychological health; becoming the decision-maker and adjusting to increased responsibility were common concerns of carers. Disclosure should be a process with time for follow-up and to ensure exploration of subsequent concerns and possible coping strategies.	1.Y 2.Y 3.Y 4.Y 5.Y 6.Y 7.Y 8.Y 9.Y 10.CA 11.N

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Von Kutzleben et al. (2012) Germany	Initial non-systematic review, then a systematic review on the subjective experiences of community dwelling persons with dementia.	No timeframe restrictions; search conducted in English, German and French; no limitations on dementia type or stage, or to age, gender or cultural characteristics of participants. Studies from electronic search (PubMed, PsycINFO, CINAHL, EMBASE, GeroLit, Cochrane Library, Google Scholar), reference lists of identified reviews and other relevant papers, and advice from colleagues and other scholars in the field. (n=6; 2002-2010). Included reviews were described as systematically conducted and of high quality with most mixed method studies.	Search restricted to review articles to complement the evidence from two papers identified in initial non-systematic review. Inclusion criteria: review to include research in home environments or out-patient settings; to contain direct self-expressions of the person with dementia distinguishable from proxy answers and evaluations by health care professionals; studies on subjective experiences of in-patient settings or data from interviews using only proxy answers were excluded. Two stage check-list used and reviews analysed using MAXQDA 10 software for a thematic analysis. 7 reviews initially – one excluded in the course of the coding process.	NA	Persons with dementia experience the whole range of human emotions, their needs do not differ from those of other groups of patients with chronic conditions. Coming to terms with the illness and maintaining normality were major themes. The need for accompanying continued support and counselling appeared central. Disclosure of the diagnosis represented a critical stage for the person and they preferred to be included in this process.	1.Y 2.Y 3.Y 4.CA 5.Y 6.Y 7.Y 8.Y 9.CA 10.CA 11.N

Notes: * Appraisal criteria from the AMSTAR measurement tool – Shea BJ, Grimshaw JM, Wells GA, Boers M, Andersson N, Hamel C, et al. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. BMC Med Res Methodol. 2007;7(1):10.

Appraisal items:

1, 'A priori' design provided; 2, duplicate study selection and data extraction; 3, comprehensive literature search performed; 4, the status of publication (i.e. grey literature) used as an inclusion criterion; 5, a list of studies (included and excluded) provided; 6, characteristics of the included studies provided; 7, scientific quality of the included studies assessed and documented; 8, scientific quality of the included studies used appropriately in formulating conclusions; 9, methods used to combine the findings of studies appropriate; 10, likelihood of publication bias assessed; 11, conflict of interest stated.

^ Where the above evidence summaries are not systematic literature reviews, the appraisals of these using this instrument were done to give some indication of the evidence reviewed. Later, the JBI Critical Appraisal Checklist for Text and Opinion Papers became available and replaced using the AMSTAR tool this way (see below).

Ratings: Yes (Y); No (N); Can't answer (CA); Not applicable (NA)

Evidence summary for text and opinion papers (communicating the diagnosis)

Reference Country	Objective	Results/findings	Quality appraisal*
Derksen et al. (2006) The Netherlands	Described a model developed to enhance the last phase of the diagnostic process – a disclosure meeting with the GP and a counselling meeting with a nurse or nurse practitioner.	When supporting people with dementia keep to the order of the phases in the disclosure meeting (i.e., introduction; sharing the diagnosis; space for emotions; further explanations; continuity of care) and to take enough time for each phase. The principles of 'breaking bad news' apply to diagnostic disclosure in dementia, but specific attention should be given to helping the person with dementia concentrate on the purpose of the disclosure meeting through a good introduction; and address the person with dementia as a partner in the conversation.	1.Y 2. Y 3. Y 4.Y 5.Y (5 refs) 6. NA
Lee & Weston (2011) Canada	Provided an educational approach on how to deliver a diagnosis of dementia	Determine what the person knows about dementia (address misconceptions); identify patients in the early stages of memory loss; focus on goals of management (in the context of the patient's world); provide realistic hope by highlighting individuality in disease manifestation and progression; emphasize that the patient will not be abandoned by their GP.	1.Y 2. Y 3. Y 4.Y 5.Y (10 refs) 6. NA
Schei, E. (2006) Norway	Proposed clinical leadership was a concept which offered practical and ethical direction to clinicians, education, health policy and research.	The author proposes that the notion of leadership highlights the ethical core of medicine, by acknowledging power asymmetry and patient vulnerability; that the GP must act in ways that respect the expectations inherent in the medical 'social contract', whilst simultaneously integrating scientific medical knowledge with knowledge of the individual's illness and situation. Education for clinical leadership needs to focus on methods and experiences that enhance self-reflection, relational skills, and empathic understanding; and clinical leadership needs to be carried out in ways that convey self-awareness and intellectual humility.	1.Y 2. Y 3. Y 4.Y 5.Y (52refs) 6. Y

Notes: * Appraisal criteria from the JBI Critical Appraisal Checklist for Text and Opinion Papers McArthur A, Klugárová J, Yan H, Florescu S. Innovations in the systematic review of text and opinion. International Journal of Evidence-Based Healthcare. 2015;13(3):188-95..

Appraisal items:

1. Is the source of the opinion clearly identified? 2. Does the source of opinion have standing in the field of expertise? 3. Are the interests of the relevant population the central focus of the opinion? 4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed? 5. Is there reference to the extant literature? 6. Is any incongruence with the literature/sources logically defended?

Ratings: Yes (Y); No (N); Unclear (U); Not applicable (NA)

Evidence summary for qualitative studies (communicating the diagnosis)

Reference Country	Objective	Participants (n=)	Method	Findings	QATSDD score*	Paper No.*
Byszewski et al. (2007) Canada	Exploratory study of patient and carer perspectives of the disclosure of a dementia diagnosis	Patients and their carers referred to a Geriatric Day Hospital; (n=30 patient-carer dyads); patients 65>85 yrs; 20 female, 10 male); 80% English as mother tongue; 50% lived alone, 13% in retirement home, 37% in carer's home. Diagnosis of dementia: Alzheimer's 44% Mixed 33%, Vascular 23%.	Data gathered by audio-recording at: the disclosure meeting; by semi- structured interviews held separately with the patient and primary carer in their homes within 1 week of disclosure; 12 carers participated in 3 focus groups within 1 month of the disclosure meeting. Audio-recordings transcribed, imported into NUD*IST 6 software along with filed notes and chart reviews. Data analysis by more than one researcher involved thematic coding using a constant comparison coding process, with review of coding and themes for consistency by four researchers.	Most patients and carers preferred full disclosure of the diagnosis. Patients expressed satisfaction with the physician giving the diagnosis and with their carers' presence at the disclosure meeting, though more information about their condition was wanted. Carers provided insight regarding the patient response; suggested the need to emphasise hope in the face of a difficult diagnosis; the use of progressive disclosure to allow the person (and carer) to prepare; and provision of detail about the illness and its progression.	76%	1
Dhedhi et al. (2014) UK	To explore GPs' perspectives on what 'timeliness' means in diagnosing dementia.	GPs (n=7) from an academic department of primary care and public health; four female, three male; aged 30 -65 yrs.; all with experience of conveying a diagnosis of dementia; general practice experience from 2-20 yrs.	Audio-recorded interviews, which were largely informant led, lasted 30 to 60 minutes; and transcribed (26 757 words). Four-step iterative narrative analysis (reading, sorting and familiarising with the text; finding themes, patterns and connections through re-reading and reflection; searching for alternatives, confirming/disconfirming data; and representing an account of what was learned in the research process) by three researchers (initially individually, then collectively).	Diagnosis of dementia is a complex medical and social practice in which GPs attend to multiple competing priorities while providing individually tailored patient care. Timeliness in the diagnosis of dementia involved balancing a range of judgements and reluctance or failure to make a diagnosis on a particular occasion commonly reflected a range of nuanced balancing judgements, often negotiated with patients and their families. GPs accounts highlighted the slow unfolding process of becoming a person with dementia – none of the GPs' examples involved reaching a diagnosis in a single consultation. Of import was the 'right' or opportune time rather than 'when' in terms of chronological time in diagnosing dementia.	81%	2

Reference Country	Objective	Participants (n=)	Method	Findings	QATSDD score*	Paper No.*
Hellstrom & Torres (2013) Sweden	Explored the disclosure preferences of people with dementia and their spouses – what couples living with dementia want to know and tell about the disease.	People with dementia (n=20; 10 females, 10 males; aged 61-80 yrs) and their spouses (n=20; 10 females, 10 males) recruited through two memory clinics. Part of a larger study; these interviews were those that contained lengthy discussions about disclosure preferences.	Semi-structured interviews with participants either jointly (n=8) or individually (n=12) at location of participants choice (home, day care centre, workplace). Interviews ranged from 18 min to two hours; were recorded, transcribed verbatim and thematically analysed.	Five preference patterns identified. Couples' preferences about what they want to know were related to what they were willing to tell –it was usually the preferences of the person that had a dementia diagnosis that guided the stand couples took as far as disclosure issues were concerned. A type of interdependence existed when one person in a couple had received the diagnosis, and the life of the two people as a couple was challenged because of this.	55%	3
Karnieli-Miller, Werner, Aharon-Peretz, & Eidelman (2007) Israel	Explored physicians' difficulties, attitudes and communication styles about the disclosure of the diagnosis of Alzheimer's disease (AD) in practice	Neurologists in a Cognitive Neurology Unit (n=3) with 13 -34 yrs. experience; diagnosed AD to 60-200 patients and carers in 6 months preceding the study. Study limited patients (n=14) at one major academic medical centre – 9 females, 5 males, age $m=78.5$ ($SD=8.415$).	Phenomenological study which combined pre-encounter semi-structured interviews with physicians, observations of actual encounters of diagnosis disclosure of AD, and post-encounter semi-structured interviews. Observations and interviews were audio-taped and transcribed verbatim. Analysis of interviews initially involved open coding for categories and themes within interviews and encounters; then interviews selectively coded for relationships between the themes and apposing relationships with one another. Observations and pre and post-interviews were analysed with the physician as a unit.	Various ways to (un)veil the bad news was perceived as different ways of dulling the impact and avoiding full and, therefore, problematic statements. In the encounters this was achieved by keeping encounters short, avoiding elaboration, confirmation of comprehension and explicit terminology and using fractured sentences. The difficulties encountered in breaking the news about AD were highlighted.	64%	4

Reference Country	Objective	Participants (n=)	Method	Findings	QATSDD score*	Paper No.*
Lecouturier, Bamford, Hughes, Francis, Foy, Johnston, & Eccles, (2008) UK	To identify important disclosure behaviours and explore whether supplementing a literature review with other methods would result in identification of new behaviours.	Literature review articles (n=108; opinion pieces, original research and reviews). Ten face-to-face interviews: people with dementia (n= 4; in two of these the informal carer was present); informal carers (n=6). Consensus panel of health and social care professionals (n=8)	Literature review; in-depth face-to-face interviews with people with dementia and informal carers (5 interviews analysed using a thematic framework); used a consensus process with health and social care professionals. Consensus panel completed a postal questionnaire of open-ended questions followed by a meeting (nominal group technique). Content analysis of the full list of behaviours was performed.	From the interviews, consensus panel and literature review 220 behaviours were elicited (109 were over-lapping). Although much literature focused on breaking bad new to people with cancer, it was highly relevant to disclosing a diagnosis of dementia (193 behaviours identified). The interviews and consensus panel produced 27 behaviours complementary to the review. Eight categories of behaviours were identified. Many of the behaviours identified in the literature (often based on professional opinion rather than empirical evidence) resonated with people with dementia and informal carers. Contradictory behaviours emphasised the need to tailor the process of disclosure to individual patients and carers.	55%	5
Robinson et al. (2008) Australia	To uncover views about dementia diagnosis, derived from a larger study on the information needs of carers of people with dementia.	Participants (total n = 101) comprised service providers from the six key provider categories including family carers, health professionals and dementia service personnel.	Participants were purposively sampled on the basis of their roles in the management of people with dementia; focus groups according to category (total focus group n = 13); lasted 60–90 minutes; tailored discussion guides focussing on questions about service providers' information needs, transfer of information between providers and access to information. Tapes were transcribed verbatim. Data relating to diagnosis were separated and ongoing content and thematic analyses conducted.	The term 'dementia' held connotations of stigma and futility, in spite of stated benefits of having a diagnosis. GPs were considered as pivotal but having inadequate diagnostic and treatment options. Most health professionals advocated a longitudinal diagnostic process, though this created considerable stress for family carers who sought a speedy process. Some dementia-specific services were undeliverable without a diagnosis. Dementia diagnosis is immersed in deep-rooted difficulties and stressful implications, which is compounded by carers' differing needs and interests. The complexity of diagnosis appears underestimated and underreported.	76%	6

Reference Country	Objective	Participants (n=)	Method	Findings	QATSDD score*	Paper No.*
Samsi, Abley, Campbell, Keady, Manthorpe, Robinson, Watts, Bond. (2014) UK	To explore the experience of the assessment and diagnostic process for people with cognitive impairment and their carers.	People with cognitive impairment (n=27) and 26 carers (n= 26) (20 dyads) from four memory services before and after diagnostic disclosure.	In-depth qualitative interviews digitally recorded and transcribed. Interview transcripts were subject to constant comparative analysis and interpretations subject to regular discussion. NVivo was used to manage data analysis.	Participants appeared to have often felt without support to manage their uncertainties and did not know where to turn for support; they were generally positive of the practice of individual professionals; some were critical of the systemic process of assessment and diagnosis disclosure. Twelve sub-themes were identified; feelings of confusion, uncertainty and anxiety over interminable waiting times dominated.	86%	7

Note: *See following QATSDD scoring of qualitative studies (communicating the diagnosis) for details

Quality Assessment Tool for Studies with Diverse Designs (QATSDD) scoring of qualitative studies (communicating the diagnosis)

Paper No (details overleaf):		1	2	3	4	5	6	7
No.	Criteria (Scored 0-3)							
1	Explicit theoretical framework	3	3	3	3	0	3	3
2	Statement of aims/objectives in main body of report	3	3	3	3	3	2	3
3	Clear description of research setting	3	3	2	2	2	3	3
4	Evidence of sample size considered in terms of analysis	2	2	0	3	0	0	3
5	Representative sample of target group of a reasonable size	2	2	2	2	2	3	3
6	Description of procedure for data collection	2	2	1	2	2	3	3
7	Rationale for choice of data collection tool(s)	3	3	1	2	2	3	3
8	Detailed recruitment data	3	3	2	2	1	2	2
9	Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative only)	2	3	2	2	2	2	2
10	Fit between research question and method of analysis	3	3	2	3	2	3	3
11	Good justification for analytic method selected	2	3	2	1	2	2	2
12	Assessment of reliability of analytic process (Qualitative only)	3	1	3	2	2	3	3
13	Evidence of user involvement in design	0	0	0	0	0	0	0
14	Strengths and limitations critically discussed	1	3	0	0	3	3	3
Total score (max 42):		32	34	23	27	23	32	36
Percentage:		76%	81%	55%	64%	55%	76%	86%

Appraisal instrument - Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52. See following page for QATSDD scoring details.

Key to papers for QATSDD scoring of qualitative articles (communicating the diagnosis)

1. Byszewski AM, Molnar FJ, Aminzadeh F, Eisner M, Gardezi F, Bassett R. Dementia diagnosis disclosure: a study of patient and caregiver perspectives. *Alzheimer Dis Assoc Disord.* 2007;21(2):107-14.
2. Dhedhi SA, Swinglehurst D, Russell J. 'Timely' diagnosis of dementia: what does it mean? A narrative analysis of GPs' accounts. *BMJ Open*4:e004439 doi:101136/bmjopen-2013-004439 2014;http://bmjopen.bmj.com/content/4/3/e004439.full.pdf+html.
3. Hellstrom I, Torres S. A wish to know but not always tell-couples living with dementia talk about disclosure preferences. *Aging & Mental Health.* 2013;17(2):157-67.
4. Karnieli-Miller O, Werner P, Aharon-Peretz J, Eidelman S. Dilemmas in the (un)veiling of the diagnosis of Alzheimer's disease: walking an ethical and professional tight rope. *Patient Educ Couns.* 2007;67:307-14.
5. Lecouturier J, Bamford C, Hughes JC, Francis JJ, Foy R, Johnston M, et al. Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'. *BMC Health Serv Res.* 2008;8:95.
6. Robinson AL, Emden CG, Elder JA, Lea EJ, Vickers JC, Turner PA. Multiple views reveal the complexity of dementia diagnosis. *Australas J Ageing.* 2008;27(4):183-8.
7. Samsi K, Abley C, Campbell S, Keady J, Manthorpe J, Robinson L, et al. Negotiating a labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *Int J Geriatr Psychiatry.* 2014;29(1):58-67.

Evidence summary for quantitative studies (communicating the diagnosis)

Reference Country	Objective	Participants (n=)	Methods	Results/findings	QATSDD score*	Paper No.*
De Lepeleire, Buntinx, & Aertgeerts (2004) Belgium	To investigate behaviour re disclosure of dementia	Flemish GPs (n=521)	Postal survey.	GPs always or usually disclosed the diagnosis, while 37% provided information about the prognosis. Most doctors (75%) saw benefits in disclosure, particularly in regards to planning care, providing treatment and encouraging a good doctor-patient relationship. 61% of GPs presented an appropriate differential diagnosis.	62%	1
Magin et al (2015) Australia	To establish levels and associations of acceptance of Alzheimer's Disease (AD) testing modalities by general practice patients.	Patients \geq 50 yrs (n=489) presenting consecutively to participating practices during 3 randomly selected half-day sessions over a 2-week period.	Cross-sectional anonymous survey: demographic data and attitudes to screening for other diseases; included the screening acceptance domain of the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) instrument, with an item regarding testing cerebral spinal fluid included. Associations of PRISM-PC scores were analysed with multiple linear regression.	Of 489 participants (response rate 87%), 66.2% would like to know if they had AD; participants were more accepting of non-invasive or familiar testing modalities (e.g. questionnaire, physician's examination, and blood test) rather than cerebral imaging or lumbar puncture. Attitudes to AD testing appeared influenced by a positive attitude to disease screening in general. Patients who self-perceived higher risk of AD were less accepting of testing, as were those with lower educational attainment (10 school years) or less.	79%	2
Mate, Pond, Magin, Goode, McElduff, & Stocks (2012) Australia	To examine the predictors of QoL in a community-dwelling population, with or without dementia.	GPs (n=169); patients aged >75 years (N=2028).	Cross-sectional study using baseline data from a RCT. Patients interviewed for information on personal circumstances; instruments administered included: the WHOQOL-BREF, Geriatric Depression Scale, GPAQ (satisfaction with GP care), and the CAMCOG-R (cognitive function). Patients with a CAMCOG-R score < 80 were allocated to the dementia group. GPs provided an independent clinical judgment of cognitive function for their patients who participated. SAS v9.2 was used for all analyses.	The dementia group had significantly lower QoL scores in all four domains of the WHOQOL-BREF; the GDS score was negatively correlated with all four domains in the non-dementia group and with physical, psychological, and environmental QoL in the dementia group (all $p < 0.001$). Satisfaction with GP communication was associated with a higher QoL in their older patients. Diagnosis and disclosure of memory problems was associated with better QoL in people with dementia.	81%	3

QATSDD scoring of quantitative studies (communicating the diagnosis)

		Paper No:		
		1	2	3
No.	Criteria (Scored 0-3)			
1	Explicit theoretical framework	3	3	3
2	Statement of aims/objectives in main body of report	3	3	3
3	Clear description of research setting	3	3	3
4	Evidence of sample size considered in terms of analysis	1	2	2
5	Representative sample of target group of a reasonable size	2	2	3
6	Description of procedure for data collection	1	3	3
7	Rationale for choice of data collection tool(s)	2	2	3
8	Detailed recruitment data	3	3	3
9	Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	1	1	1
10	Fit between stated research question and method of data collection (Quantitative only)	2	3	3
11	Fit between research question and method of analysis	2	3	3
12	Good justification for analytic method selected	1	3	2
13	Evidence of user involvement in design	1	0	0
14	Strengths and limitations critically discussed	1	2	2
Total score (max 42):		26	33	34
Percentage:		62%	79%	81%

*Appraisal instrument - Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. *J Eval Clin Pract.* 2012;18(4):746-52. See following page for QATSDD scoring details.

Key to papers for Communicating the diagnosis: Evidence summary for quantitative studies:

1. De Lepeleire J, Buntinx F, Aertgeerts B. Disclosing the diagnosis of dementia: the performance of Flemish general practitioners. *Int Psychogeriatr.* 2004;16(4):421-8.
2. Magin P, Juratowitch L, Dunbabin J, McElduff P, Goode S, Tapley A, et al. Attitudes to Alzheimer's disease testing of Australian general practice patients: a cross-sectional questionnaire-based study. *Int J Geriatr Psychiatry.* 2015;31(4):361-6.
3. Mate KE, Pond CD, Magin PJ, Goode SM, McElduff P, Stocks NP. Diagnosis and disclosure of a memory problem is associated with quality of life in community based older Australians with dementia. *Int Psychogeriatr.* 2012;24(12):1962-71.

Evidence summary for mixed method studies (communicating the diagnosis)

Reference Country	Objective	Participants (n=)	Methods	Results/findings	QATSDD score*	Paper No.*
Elson P. (2006) UK	Explored the views of patients prior to diagnosis of dementia	Patients aged ≥ 65 yrs. referred to an Old Age Psychiatry Service for investigation of memory complaints (n=95). Of these 59 denied suffering memory difficulties. This left n=36 (22 female, 14 male); age $m= 75.86$ yrs. (SD 5.82); m MMSE score = 24.58 (SD 4.18) for interviews.	Detailed cognitive assessment conducted over either one or two sessions by a clinical psychologist (the author) either in an outpatient memory clinic or on a domiciliary basis. The interviews explored participants' perspectives. They were asked what they considered to be the possible cause of their memory problem. They were asked if they would want to know if diagnosed with Alzheimer's disease and their reasons for this. Descriptive statistics including percentages incorporated into results.	Two-thirds of patients were uncertain about the cause of their memory problems though the remainder offered explanations. Eighty-six per cent wanted to know the cause; 69% wanted to know if diagnosed with Alzheimer's disease, and a variety of reasons were given to support their preference. Most older adults presenting to services with memory complaints appear to have little understanding of the potential cause of their problems, though wished to know the cause, even if this was Alzheimer's disease.	50%	1
Mastwyk, Ames, Ellis, Chiu, & Dow (2014) Australia	To explore how information should be presented in the feedback session following assessment of memory impairment.	Patients (n=32) and carers (n=32) at the MRDC, St George's Hospital, Melbourne; Melbourne Health's Cognitive Dementia and Memory Services (CDAMS) and private patients of two associated of the National Ageing Research Institute	Thirty-two semi-structure interviews with patients and carers: first, at the clinic visit after the feedback session; second at their next clinic visit (av. 15 weeks later) – 18 interviews. Interviews transcribed. Details of feedback sheets recorded as data. Quantitative and qualitative data were entered into the Predictive Analytic Software Package. Qualitative data were counted by frequency; descriptive statistics; and t-tests used to measure correlation between MMSE scores and recall/non-recall of the diagnosis.	Recall of information from the feedback session was variable. Most respondents thought a direct approach best to inform the patient of a dementia diagnosis; written information and compassion demonstrated by the doctor were helpful. Opinions on whether to give all the information at once or in stages were divided. The current format of the feedback session needs revision to improve recall.	52%	2

QATSDD scoring of mixed method articles (communicating the diagnosis)

		Paper No:	
		1	2
No.	Criteria (Scored 0-3)		
1	Explicit theoretical framework	2	2
2	Statement of aims/objectives in main body of report	3	2
3	Clear description of research setting	3	2
4	Evidence of sample size considered in terms of analysis	1	2
5	Representative sample of target group of a reasonable size	2	2
6	Description of procedure for data collection	1	2
7	Rationale for choice of data collection tool(s)	0	1
8	Detailed recruitment data	1	2
9	Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	2	0
10	Fit between stated research question and method of data collection (Quantitative only)	3	3
11	Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative only)	1	2
12	Fit between research question and method of analysis	2	2
13	Good justification for analytic method selected	0	1
14	Assessment of reliability of analytic process (Qualitative only)	0	0
15	Evidence of user involvement in design	0	0
16	Strengths and limitations critically discussed	3	2
Total score (max 48):		24	25
Percentage:		50%	52%

* Appraisal instrument - Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52. See following page for QATSDD scoring details

Key to papers:

1. Elson P. Do older adults presenting with memory complaints wish to be told if later diagnosed with Alzheimer's disease? Int J Geriatr Psychiatry. 2006;21:419-25.
2. Mastwyk M, Ames D, Ellis KA, Chiu E, Dow B. Disclosing a dementia diagnosis: what do patients and family consider important? Int Psychogeriatr. 2014;26(8):1263-72.

Grey literature appraisal (communicating the diagnosis)

Instrument: AACODS		Reference: Alzheimer's Australia Victoria. Perceptions of dementia in ethnic communities Hawthorn, Victoria 2008 [cited 2017 April 17].	YES	NO	?
Authority	<i>Identifying who is responsible for the intellectual content.</i>				
	Individual author:				
	• Associated with a reputable organisation?				
	• Professional qualifications or considerable experience?				
	• Produced/published other work (grey/black) in the field?				
	• Recognised expert, identified in other sources?	x			
	• Cited by others? (use Google Scholar as a quick check)				
	• Higher degree student under "expert" supervision?				
	Organisation or group:				
	• Is the organisation reputable? (e.g. W.H.O)	x			
	• Is the organisation an authority in the field?	x			
In all cases:					
• Does the item have a detailed reference list or bibliography?			x		
Accuracy	• Does the item have a clearly stated aim or brief?	x			
	• Is so, is this met?	x			
	• Does it have a stated methodology?		x		
	• If so, is it adhered to?				
	• Has it been peer-reviewed?	x			
	• Has it been edited by a reputable authority?	x			
	• Supported by authoritative, documented references or credible sources?	x			
	• Is it representative of work in the field?				
	• If No, is it a valid counterbalance?				
	• Is any data collection explicit and appropriate for the research?			x	
	• If item is secondary material (e.g. a policy brief of a technical report) refer to the original. Is it an accurate, unbiased interpretation or analysis?				
Coverage	<i>All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question or be based on statistics from a particular survey.</i>				
	• Are any limits clearly stated?	x			
Objectivity	It is important to identify bias, particularly if it is unstated or unacknowledged.				
	• Opinion, expert or otherwise, is still opinion: is the author's standpoint clear? • Does the work seem to be balanced in presentation?	x			
Date	<i>For the item to inform your research, it needs to have a date that confirms relevance</i>				
	• Does the item have a clearly stated date related to content? No easily discernible date is a strong concern.	x			
	• If no date is given, but can be closely ascertained, is there a valid reason for its absence?				
	• Check the bibliography: have key contemporary material been included?				
Significance	<i>This is a value judgment of the item, in the context of the relevant research area</i>				
	• Is the item meaningful? (this incorporates feasibility, utility and relevance)?	x			
	• Does it add context?	x			
	• Does it enrich or add something unique to the research?	x			
	• Does it strengthen or refute a current position?				x
	• Would the research area be lesser without it?	x			
	• Is it integral, representative, typical?	x			
• Does it have impact? (in the sense of influencing the work or behaviour of others)	x				

Appraisal instrument: Tyndall J. Authority, accuracy, coverage, objectivity, date and significance scale (AACODS) 2010 [Available from: https://dspace.flinders.edu.au/xmlui/bitstream/handle/2328/3326/AACODS_Checklist.pdf;jsessionid=2EB4A7A580B36D6D06FFD6428FB02920?sequence=4]

Grey literature appraisal (communicating the diagnosis)

Instrument: AACODS	Reference: Dementia Australia. Dementia language guidelines n.d. [cited 2017 April 18]. Available from: https://www.dementia.org.au/resources/dementia-language-guidelines .	YES	NO	?
Authority	<i>Identifying who is responsible for the intellectual content.</i>			
	Individual author:			
	• Associated with a reputable organisation?			
	• Professional qualifications or considerable experience?			
	• Produced/published other work (grey/black) in the field?			
	• Recognised expert, identified in other sources?			
	• Cited by others? (use Google Scholar as a quick check)			
	• Higher degree student under “expert” supervision?			
	Organisation or group:			
	• Is the organisation reputable? (e.g. W.H.O)	x		
	• Is the organisation an authority in the field?	x		
In all cases:				
• Does the item have a detailed reference list or bibliography?		x		
Accuracy	• Does the item have a clearly stated aim or brief?	x		
	• Is so, is this met?	x		
	• Does it have a stated methodology?		x	
	• If so, is it adhered to?			
	• Has it been peer-reviewed?	x		
	• Has it been edited by a reputable authority?	x		
	• Supported by authoritative, documented references or credible sources?			
	• Is it representative of work in the field?	x		
	• If No, is it a valid counterbalance?			
	• Is any data collection explicit and appropriate for the research?		x	
	• If item is secondary material (e.g. a policy brief of a technical report) refer to the original. Is it an accurate, unbiased interpretation or analysis?			
Coverage	<i>All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question or be based on statistics from a particular survey.</i>			
	• Are any limits clearly stated?	x		
Objectivity	It is important to identify bias, particularly if it is unstated or unacknowledged.			
	• Opinion, expert or otherwise, is still opinion: is the author’s standpoint clear?	x		
	• Does the work seem to be balanced in presentation?	x		
Date	<i>For the item to inform your research, it needs to have a date that confirms relevance</i>			
	• Does the item have a clearly stated date related to content? No easily discernible date is a strong concern.		x	
	• If no date is given, but can be closely ascertained, is there a valid reason for its absence?			
	• Check the bibliography: have key contemporary material been included?			
Significance	<i>This is a value judgment of the item, in the context of the relevant research area</i>			
	• Is the item meaningful? (this incorporates feasibility, utility and relevance)?	x		
	• Does it add context?	x		
	• Does it enrich or add something unique to the research?	x		
	• Does it strengthen or refute a current position?	x		
	• Would the research area be lesser without it?	x		
	• Is it integral, representative, typical?	x		
	• Does it have impact? (in the sense of influencing the work or behaviour of others)	x		

Appraisal instrument: Tyndall J. Authority, accuracy, coverage, objectivity, date and significance scale (AACODS) 2010 [Available from: https://dspace.flinders.edu.au/xmlui/bitstream/handle/2328/3326/AACODS_Checklist.pdf;jsessionid=2EB4A7A580B36D6D06FFD6428FB02920?sequence=4]

Search strategy summary (communicating the diagnosis)

Medline	PsycINFO	EMBASE
<p>1. (general practitioner or primary care physician or family physician).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>2. (primary health care or general practice or family medicine or family practice).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>3. 1 or 2</p> <p>4. dementia.mp. or Delirium, Dementia, Amnestic, Cognitive Disorders/ or Frontotemporal Dementia/ or AIDS Dementia Complex/ or Dementia, Vascular/ or Dementia/ or Dementia, Multi-Infarct/</p> <p>5. dementia.mp. or Amnestic, Cognitive Disorders/ or Frontotemporal Dementia/ or AIDS Dementia Complex/ or Dementia, Vascular/ or Dementia/ or Dementia, Multi-Infarct/</p> <p>6. Alzheimer Disease/ or Alzheimer\$.mp.</p> <p>7. (diagnos* or manage* or disclos* or communicat* or discuss* or consult*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>8. (refer* and specialist).mp. or Specialization/ [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>9. (legal or financi*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>10. 4 or 6</p>	<p>1. (general practitioner or primary care physician or family physician).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>2. (primary health care or general practice or family medicine or family practice).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>3. 1 or 2</p> <p>4. (Alzheimer\$ or Dementia).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>5. (diagnos* or manage* or disclos* or communicat* or discuss* or consult*).mp. or Physician-Patient Relations/ or patient doctor communication.mp. or Counseling/ or counsel*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>6. 3 and 4 and 5</p> <p>7. (refer* or specialist).mp. or Specialization/ [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>8. 6 and 7</p> <p>9. (legal or financi*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>10. 6 and 9</p> <p>11. 6</p> <p>12. limit 11 to (human and english language and abstracts and yr="2008 -Current")</p> <p>13. 8</p> <p>14. limit 13 to (human and english language and abstracts and yr="2008 -Current")</p> <p>15. 10</p> <p>16. limit 15 to (human and english language and abstracts and yr="2008 -Current")</p> <p>17. Vascular Dementia/ or Dementia/ or Semantic Dementia/ or AIDS Dementia Complex/ or Presenile</p>	<p>1. (general practitioner or primary care physician or family physician).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>2. (primary health care or general practice or family medicine or family practice).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>3. 1 or 2</p> <p>4. (Alzheimer\$ or Dementia).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>5. (diagnos* or manage* or disclos* or communicat* or discuss* or consult*).mp. or Physician-Patient Relations/ or patient doctor communication.mp. or Counseling/ or counsel*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>6. 3 and 4 and 5</p> <p>7. (refer* or specialist).mp. or Specialization/ [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>8. 6 and 7</p> <p>9. (legal or financi*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>10. 6 and 9</p> <p>11. remove duplicates from 6</p> <p>12. limit 11 to (abstracts and human and english language and yr="2008 -Current")</p> <p>13. remove duplicates from 8</p> <p>14. limit 8 to (abstracts and human and english language and yr="2008 -Current")</p> <p>15. remove duplicates from 10</p>

Medline	PsycINFO	EMBASE
11. limit 10 to (abstracts and english language and humans and yr="2008 -Current") 12. 11 and 3 13. 7 and 12 14. 8 and 12 15. 9 and 12 16. 5 or 6 17. limit 16 to (abstracts and english language and humans and yr="2008 -Current") 18. 3 and 17 19. 7 and 18 20. 8 and 18 21. 9 and 18	Dementia/ or dementia.mp. or Dementia with Lewy Bodies/ or Senile Dementia/ 18. Alzheimer's Disease/ or Alzheimer\$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] 19. 17 or 18 20. (general practitioner or primary care physician or family physician).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] 21. (primary health care or general practice or family medicine or family practice).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] 22. 20 or 21 23. 19 and 22 24. 5 and 23	16. limit 15 to (abstracts and human and english language and yr="2008 -Current") 17. HIV associated dementia/ or semantic dementia/ or dementia assessment/ or "mixed depression and dementia"/ or Pick presenile dementia/ or dementia/ or senile dementia/ or multiinfarct dementia/ or frontal variant frontotemporal dementia/ or Cornell Scale for Depression in Dementia/ or Clinical Dementia Rating/ or dementia.mp. or presenile dementia/ or frontotemporal dementia/ 18. Alzheimer\$.mp. or Alzheimer disease/ 19. 17 or 18
PHCRIS search strategy <i>Communicating the Diagnosis</i>: Topic: General Practitioners; Keywords: disclos* and diagnos* and dementia or Alzheimer*; Published date: last 10 years		

Evidence summary for literature reviews (enhancing communication)

Reference Country	Study Design/ level of evidence	Sample characteristics (n=)	Intervention	Results/findings	Quality appraisal*^
Iliffe et al (2009) UK	Narrative review on the roles of GPs in caring for people with dementia in the community.	Updated from Jan 2006 the systematic review carried out for the NICE/SCIE Guidelines, Cochrane Reviews identified, and other publications obtained by consultation with experts.	NA	There is insufficient evidence of benefit to justify population screening, but earlier recognition of people with dementia is possible. Diagnosis of dementia is a shared responsibility between generalist and specialist disciplines. GPs should explore patients' ideas and concerns around their symptoms prior to referral and tentatively discuss possible diagnoses. When the diagnosis is confirmed, the GP should provide both practical and emotional support and refer for additional psychosocial support if required	1.NA 2.NA 3.Y 4.CA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.Y
Ouldred & Bryant (2008) UK	Non-systematic literature review exploring the management of dementia including coping strategies and tips on effective communication	NA	NA	Management of dementia should focus on the maintenance of the person's function and independence; modification of vascular risk factors is important in all dementias; neuropsychological and behavioural problems are common in people with dementia and various non-pharmacological interventions are available; carers can be supported by a number of interventions, including provision of information, education and training; points to improve communication with people with dementia were provided.	1.NA 2.NA 3.CA 4.Y 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.N
Seimens & Hazelton (2011) Canada	Non-systematic review about communicating with families of persons with dementia providing a practical guide to relieving carer stress	NA	NA	Essential for family physicians to work with families of dementia patients on a continuing bases; resources such as the Alzheimer's society can provide valuable information; diagnosis is a key moment – and evolving progressive disclosure beginning when cognitive impairment is first suspected can counterbalance communication difficulties around uncertainty surrounding diagnosis; the susceptibility of the carer to stress-related health issues should be assessed and the carer supported; involve the carer in the decision-making process whenever possible; make families aware of respite options; physician acknowledgement of the health of the carer is necessary to the health of the care-recipient important.	1.NA 2.NA 3.CA 4.NA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.CA

Reference Country	Study Design/ level of evidence	Sample characteristics (n=)	Intervention	Results/findings	Quality appraisal*^
Weirather (2010) USA	Non-systematic literature review discussing communication strategies to assist communication with persons with dementia	NA	NA	Described different strategies which may assist communication with someone who has dementia. Communication strategies were for issues pertaining to poor comprehension and it was suggested that the simple techniques discussed could be implemented GPs and carers; that the techniques may promote more successful communications, and ease in the way that health information may be accepted by a patient.	1. N 2.NA 3.CA 4.Y 5.NA 6.NA 7.NA 8.NA 9.NA 10.NA 11. N.

Notes: * Appraisal criteria from the AMSTAR measurement tool Shea BJ, Grimshaw JM, Wells GA, Boers M, Andersson N, Hamel C, et al. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. BMC Med Res Methodol. 2007;7(1):10.

^ Where the above evidence summaries are not systematic literature reviews, the appraisals of these using this instrument were done to give some indication of the evidence reviewed. Later, the JBI Critical Appraisal Checklist for Text and Opinion Papers became available and replaced using the AMSTAR tool this way (see below).

Appraisal items:

1, ‘A priori’ design provided; 2, duplicate study selection and data extraction; 3, comprehensive literature search performed; 4, the status of publication (i.e. grey literature) used as an inclusion criterion; 5, a list of studies (included and excluded) provided; 6, characteristics of the included studies provided; 7, scientific quality of the included studies assessed and documented; 8, scientific quality of the included studies used appropriately in formulating conclusions; 9, methods used to combine the findings of studies appropriate; 10, likelihood of publication bias assessed; 11, conflict of interest stated.

Ratings: Yes (Y); No (N); Can’t answer (CA); Not applicable (NA)

Evidence summary for text and opinion papers (enhancing communication)

Reference Country	Objective	Results/findings	Quality appraisal*
Derksen et al. (2006) The Netherlands	Described a model developed to enhance the last phase of the diagnostic process – a disclosure meeting with the GP and a counselling meeting with a nurse or nurse practitioner.	When supporting people with dementia keep to the order of the phases in the disclosure meeting (i.e., introduction; sharing the diagnosis; space for emotions; further explanations; continuity of care) and to take enough time for each phase. The principles of 'breaking bad news' apply to diagnostic disclosure in dementia, but specific attention should be given to helping the person with dementia concentrate on the purpose of the disclosure meeting through a good introduction; and address the person with dementia as a partner in the conversation.	1.Y 2. Y 3. Y 4.Y 5.Y (5 refs) 6. NA

Notes: * Appraisal criteria from the JBI Critical Appraisal Checklist for Text and Opinion Papers – McArthur A, Klugárová J, Yan H, Florescu S. Innovations in the systematic review of text and opinion. International Journal of Evidence-Based Healthcare. 2015;13(3):188-95.

Appraisal items:

1. Is the source of the opinion clearly identified? 2. Does the source of opinion have standing in the field of expertise? 3. Are the interests of the relevant population the central focus of the opinion? 4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed? 5. Is there reference to the extant literature? 6. Is any incongruence with the literature/sources logically defended?

Ratings: Yes (Y); No (N); Unclear (U); Not applicable (NA)

Evidence summary for qualitative studies (enhancing communication)

Reference Country	Objective	Participants (n=)	Method	Findings	QATSDD score*	Paper No.*
Hyden (2011) Sweden	To investigate narrative collaboration and scaffolding in dementia.	One case involving a person with mid- to late-stage AD (academic background) and his wife (former secretary and mother of three). The couple had been married nearly 50 years (around 70 years of age).	Analysed a case of collaborative storytelling. One interview of a larger corpus of interviews of couples in which one spouse had been diagnosed with AD. Interviews conducted in the couple's home. Couples were tasked with telling about how they met, and about finding out about the AD — how it was to be diagnosed and how to live with AD.	Storytelling involving persons with AD can be seen as a collaborative activity. Two tellers contribute to the story; one of the storytellers assumes more responsibility both for elaborating and pursuing the storyline as well as for organizing the interaction (narrative scaffolding). Scaffolding the collaboration may enable both participants to jointly tell a story about the shared past. Telling stories together with a person with fairly advanced dementia involves extensive repair work – stories told by persons with AD are often examples of creative attempts to deal with constraints imposed by the dementia, usually in collaboration with other participants.	55%	1
Lecouturier, Bamford, Hughes, Francis, Foy, Johnston, & Eccles, (2008) UK	To identify important disclosure behaviours and explore whether supplementing a literature review with other methods would result in identification of new behaviours.	Literature review articles (n=108; opinion pieces, original research and reviews). Ten face-to-face interviews: people with dementia (n= 4; in two of these the informal carer was present); informal carers (n=6). Consensus panel of health and social care professionals (n=8)	Literature review; in-depth face-to-face interviews with people with dementia and informal carers (5 interviews analysed using a thematic framework); used a consensus process with health and social care professionals. Consensus panel completed a postal questionnaire of open-ended questions followed by a meeting (nominal group technique). Content analysis of the full list of behaviours was performed.	From the interviews, consensus panel and literature review 220 behaviours were elicited (109 were over-lapping). Although much literature focused on breaking bad news to people with cancer, it was highly relevant to disclosing a diagnosis of dementia (193 behaviours identified). The interviews and consensus panel produced 27 behaviours complementary to the review. Eight categories of behaviours were identified. Many of the behaviours identified in the literature (often based on professional opinion rather than empirical evidence) resonated with people with dementia and informal carers. Contradictory behaviours emphasised the need to tailor the process of disclosure to individual patients and carers.	62%	2

Reference Country	Objective	Participants (n=)	Method	Findings	QATSDD score*	Paper No.*
Smith et al (2011) Australia	To translate research-based knowledge from neuropsychology, psychogeriatrics, nursing and speech pathology into a program of practical strategies for use by family and professional carers of people with dementia.	The research team included people from neuropsychology, speech pathology, nursing, and psychogeriatrics. They collaborated with aged care service providers and consumers at home.	Using a knowledge-translation framework, the project team identified facilitative/compensatory strategies to assist with common difficulties, and structured these under the mnemonics RECAPS (for memory) and MESSAGE (for communication). The information was adapted for presentation in a DVD-based education program in accord with known characteristics of effective caregiver education.	A DVD produced which comprised information on the nature and importance of memory and communication in everyday life; explanations of common patterns of difficulty and preserved ability in memory and communication through the stages of dementia; acted vignettes demonstrating strategies, based on authentic samples of speech in dementia; and scenarios to encourage the viewer to consider the benefits of using the strategies. Future development to include incorporation of consumer feedback,	67%	3

See QATSDD scoring of qualitative studies (enhancing communication) for details

QATSDD scoring of qualitative studies (enhancing communication)

		Paper No:		
		1	2	3
No.	Criteria (Scored 0-3)			
1	Explicit theoretical framework	3	3	3
2	Statement of aims/objectives in main body of report	3	3	3
3	Clear description of research setting	3	2	3
4	Evidence of sample size considered in terms of analysis	2	0	0
5	Representative sample of target group of a reasonable size	1	2	2
6	Description of procedure for data collection	2	2	1
7	Rationale for choice of data collection tool(s)	2	2	3
8	Detailed recruitment data	0	1	1
9	Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative only)	2	2	3
10	Fit between research question and method of analysis	3	2	3
11	Good justification for analytic method selected	2	2	2
12	Assessment of reliability of analytic process (Qualitative only)	0	2	1
13	Evidence of user involvement in design	0	0	3
14	Strengths and limitations critically discussed	0	3	0
Total score (max 42):		23	26	28
Percentage:		55%	62%	67%

Note: * Appraisal criteria from Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. *J Eval Clin Pract.* 2012;18(4):746-52.

Key to papers for QATSDD scoring of qualitative articles:

- Hydén L-C. Narrative collaboration and scaffolding in dementia. *Journal of Aging studies.* 2011;25:339-47.
- Lecouturier J, Bamford C, Hughes JC, Francis JJ, Foy R, Johnston M, et al. Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'. *BMC Health Serv Res.* 2008;8:95.
- Smith ER, Broughton M, Baker R, Pachana NA, Angwin AJ, Humphreys MS, et al. Memory and communication support in dementia: research-based strategies for caregivers. *Int Psychogeriatr.* 2011;23(2):256-63.

Evidence summary for qualitative studies (enhancing communication)

Reference Country	Objective	Participants (n=)	Method	Results/findings	QATSDD*	Paper no.*
Pashek & DiVenere (2006) USA	To investigate comprehension of commands presented in two rates of speech and two gesture conditions in adults with mild-to-moderate Alzheimer's disease (AD)	Adults with probable mild to moderate AD, as diagnosed by a neurologist experienced in assessment of older adults with memory impairments (n=17).	A within-subjects design was used to evaluate comprehension of two-part commands using common objects and actions presented at either a "normal" or "fast-normal" rate of speech, which were accompanied by either meaningful (pantomime) gestures or no gestures. Ten commands presented in four conditions. Participants completed pre-test measures (predictor variables). Experimental sessions were audio and video recorded.	Gestures facilitated comprehension in 16 of 17 subjects; speech rate alone did not significantly affect comprehension; comprehension was maximized for the group when fast normal commands were accompanied by gestures; and the results suggest the use of gestures may play a critical role in facilitating comprehension in individuals with mild-to-moderate AD.	74%	1
Schmidt et al. (2009) USA	To understand the nature of each individual's verbal participation in triadic interactions amongst AD patients, carers, and GPs.	AD patients (n=23) Carers (n=23) GPs (n=20)	Compared verbal participation (percent of total visit speech) by each participant in patient/caregiver/GP triads with 23 triads audio taped during a routine primary care visit. Rates of verbal participation were described and the influence of patient cognitive status (MMSE score, verbal fluency) on verbal participation were assessed.	GP verbal participation was highest at 53% of total visit speech, followed by carers (31%) and patients (16%). Patient cognitive measures were associated with patient and caregiver verbal participation, but not with GP participation. Carer satisfaction with interpersonal treatment by GP was positively related to carer's own verbal participation. Carers of AD patients and GPs maintain active, coordinated verbal participation in consultations while patients participate less.	60%	2

Reference Country	Objective	Participants (n=)	Method	Results/findings	QATSDD*	Paper no.*
Small & Gutman (2002) Canada	To review the AD caregiving literature to identify communication strategies commonly recommended for carers, and to determine how often carers report using these strategies and how effective they find them.	Carers for spouses diagnosed with AD (n=20), 9 males, 11 females.	A 10-item questionnaire was constructed that listed 10 strategies generated from the literature search (presented in a fixed random order different from the rank order derived from the literature). Participants responded on Likert scales to indicate frequency of use of each strategy, and how much they felt the strategy improved communications. Descriptive, correlational analysis.	Many of the strategies which appeared in the literature were those carers reported using and perceived as effective (carers' perceived use of strategies and their effectiveness was positively correlated). Carers perceived using the 10 strategies, but the strategies which appeared most frequently in the literature were not necessarily the ones most often used by carers. Results showed that carers were aware of their communication behaviour and modified it in ways that they thought improved communication with their spouse.	50%	3

See QATSDD scoring of quantitative studies (enhancing communication) for details

QATSDD scoring of quantitative studies (enhancing communication)

		Paper No:		
		1	2	3
No.	Criteria (Scored 0-3)			
1	Explicit theoretical framework	3	2	3
2	Statement of aims/objectives in main body of report	3	3	3
3	Clear description of research setting	3	3	3
4	Evidence of sample size considered in terms of analysis	3	1	0
5	Representative sample of target group of a reasonable size	2	2	1
6	Description of procedure for data collection	2	2	2
7	Rationale for choice of data collection tool(s)	2	2	2
8	Detailed recruitment data	2	2	2
9	Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	0	0	0
10	Fit between stated research question and method of data collection (Quantitative only)	2	1	2
11	Fit between research question and method of analysis	2	3	2
12	Good justification for analytic method selected	3	2	1
13	Evidence of user involvement in design	2	0	0
14	Strengths and limitations critically discussed	2	2	0
Total score (max 42):		31	25	21
Percentage:		74%	60%	50%

Note: * Appraisal criteria from Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52.

Key to papers:

1. Pashek GV, DiVenere E. Auditory comprehension in Alzheimer disease: influences of gesture and speech rate. J Med Speech Lang Pathol. 2006;14(3):143-55.
2. Schmidt KL, Lingler JH, Schulz R. Verbal communication among Alzheimer's disease patients, their caregivers, and primary care physicians during primary care office visits. Patient Educ Couns. 2009;77(2):197-201.
3. Small JA, Gutman G. Recommended and reported use of communication strategies in Alzheimer caregiving. Alzheimer Dis Assoc Disord. 2002;16(4):270-8..

Search strategy summary (communication strategies in general consultations involving dementia)

Medline	PsycINFO	EMBASE
<p>1. (general practitioner or primary care physician or family physician or primary health care or general practice or family medicine or family practice).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>2. dementia.mp. or Delirium, Dementia, Amnestic, Cognitive Disorders/ or Frontotemporal Dementia/ or AIDS Dementia Complex/ or Dementia, Vascular/ or Dementia, Multi-Infarct/</p> <p>3. Alzheimer Disease/ or Alzheimer\$.mp.</p> <p>4. 2 or 3</p> <p>5. (diagnos* or disclos* or communicat*).mp. or discuss*or consult*or Communication/ or Physician-Patient Relations/ or doctor-patient communication.mp. or Professional-Patient Relations/ or Communication Barriers/ [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>6. 1 and 4 and 5</p> <p>7. 6</p> <p>8. limit 7 to (abstracts and english language and humans and yr="2008 -Current")</p> <p>9. communicat*.tw.</p> <p>10. 8 and 9</p>	<p>1. (general practitioner or primary care physician or family physician or primary health care or general practice or family medicine or family practice).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>2. Vascular Dementia/ or Dementia/ or Semantic Dementia/ or AIDS Dementia Complex/ or Presenile Dementia/ or dementia.mp. or Dementia with Lewy Bodies/ or Senile Dementia/</p> <p>3. Alzheimer's Disease/ or Alzheimer\$.mp.</p> <p>4. 2 or 3</p> <p>5. (diagnos* or disclos* or communicat* or discuss*or consult*).mp. or Interpersonal Communication/ or Communication/ or doctor-patient communication.mp. or Medical Patients/ or Therapeutic Processes/ or Medical Education/ or Communication Skills/ [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>6. 1 and 4 and 5</p> <p>7. 6</p> <p>8. limit 7 to (human and english language and abstracts and yr="2008 -Current")</p> <p>9. communicat*.tw.</p> <p>10. 8 and 9</p>	<p>1. (general practitioner or primary care physician or family physician or primary health care or general practice or family medicine or family practice).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>2. HIV associated dementia/ or semantic dementia/ or dementia assessment/ or "mixed depression and dementia"/ or Pick presenile dementia/ or dementia/ or senile dementia/ or multiinfarct dementia/ or frontal variant frontotemporal dementia/ or Cornell Scale for Depression in Dementia/ or Clinical Dementia Rating/ or dementia.mp. or presenile dementia/ or frontotemporal dementia/</p> <p>3. Alzheimer\$.mp. or Alzheimer disease/</p> <p>4. 2 or 3</p> <p>5. (diagnos* or disclos* or communicat* or discuss*or consult*).mp. or interpersonal communication/ or communication disorder/ or doctor patient relation/ or communicat*.mp. or communication skill/ or consultation/ or psychological aspect/ or interpersonal communication/ or doctor patient relation/ or communication skill/ or doctor-patient communication.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>6. communicat*.tw.</p> <p>7. 1 and 4 and 5</p> <p>8. 6 and 7</p> <p>9. 8</p> <p>10. limit 9 to yr="2008 -Current"</p>
<p>PHCRIS search strategy: Topic: General Practitioners; Keywords: dementia or Alzheimer* and communicat*; Published date: last 10 years</p>		