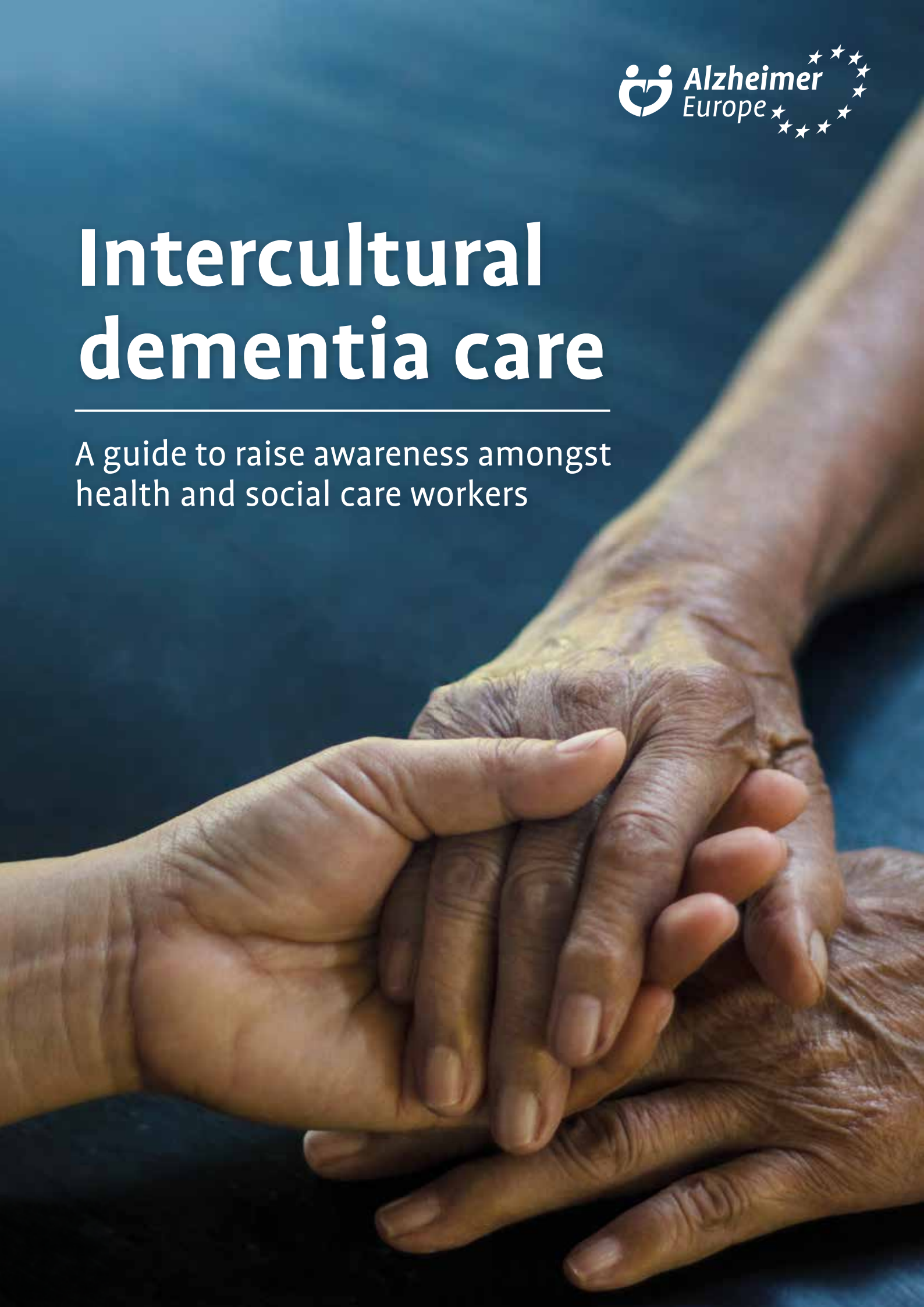


Intercultural dementia care

A guide to raise awareness amongst
health and social care workers



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Introduction

The aim of this guide is to help you, as a health and social care worker, to provide dementia care, which corresponds to the needs and wishes of people from a wide range of ethnic groups, especially minority ethnic groups.

Many people came to Europe in the 1950s to the 1980s to work and are now reaching an age when the risk of developing dementia is higher. Some minority ethnic communities tend to have higher levels of diabetes, hypertension and cardiovascular disease. This puts them at a higher risk of developing dementia.

It is still not known exactly how many people from different ethnic groups in Europe have dementia. However, the number is clearly increasing and at a relatively high rate in some communities. Research and various surveys have shown that people with dementia and their relatives from minority ethnic groups do not use health care services, such as day care, home care and respite care to the same extent as other people do. When trying to provide good quality dementia care to people from all ethnic groups, you may be faced with challenges, such as:

- how to reach people with dementia and carers who need support and care,
- how to understand people's needs and wishes in the light of different values and traditions,
- how to establish trust,
- how to tackle racism and discrimination (especially within the healthcare system),
- how to provide person-centred care,
- how to overcome barriers linked to language and education,
- how to adapt care and support to religious beliefs and cultural traditions.

There are no neat, readymade answers to these questions because every situation is different and involves different people, at different moments in time, looking for solutions within different social and healthcare systems. However, it is possible to develop an approach to working with and supporting people from all ethnic groups that will gradually increase your ability to provide good quality intercultural care and support. This guide draws on the experience and know-how of a group of experts and builds on two other reports¹ by people with knowledge and direct experience of providing dementia care to people from many different ethnic communities. Members of the working group identified with a range of different ethnic groups and had different geographical origins and religions. The European Working Group of People with Dementia provided contacts, shared their experience and commented on the various drafts. The guide has been developed thanks to continued funding from the Robert Bosch Stiftung.

1) 'The development of intercultural care and support for people with dementia from minority ethnic groups', which was published by Alzheimer Europe in 2018 with funding from the European Union and the Robert Bosch Stiftung, and a shorter version inspired by this report, which was published by the Nordic Welfare Centers theme network for dementia and ethnic minorities.



Chapter 1. About minority ethnic groups and dementia



Ethnicity and ethnic minority groups/communities

An ethnic community is made up of people who have things in common (such as language, religion, traditions and values) that make them feel part of a group. They do not necessarily live close to each other or even know each other personally. For many people, ethnicity is a fundamental aspect of their identity – of who and what they are. It is not something that is biologically determined and not everyone who identifies with a particular ethnic group agrees with all of its principles and values or practices all its traditions.

Ethnicity is not something that only other people have and it is not an issue of ‘them’ and ‘us’. As societies become more multi-cultural, people gradually adapt to each other’s cultures, values and traditions. This has been happening for centuries. The most recent examples can be seen with food (e.g. Italian, Indian and Chinese cuisine), fashion, music and language. Ethnic groups are therefore formed through an ongoing, flexible process with individuals and groups adapting to each other, without this threatening their personal identity, culture or sense of belonging to the group.

The use of the term ‘minority ethnic group’ emphasises two things, namely that everyone is from an ethnic group and that some ethnic groups are smaller than others. We are not using the terms ‘migrant’ and ‘immigrant’ in this guide because they mean different things in different countries and because many members of minority ethnic groups have no direct personal experience of migration. People from minority ethnic groups sometimes live together amongst others who come from the same country (or that of their parents or grandparents) and often have the same religion. Some people were born and brought up in the country where they are now living but may still consider themselves as part of a minority ethnic community. Many also identify fully or equally with a particular national identity (e.g. describing themselves as ‘British Asian’ or ‘Dutch Indonesian’ etc.).

Formal definitions of dementia

Let’s now look at what dementia is. Dementia is a syndrome (a group of symptoms that typically occur together). In most cases, it is caused by an incurable disease, such as Alzheimer’s disease, or by brain damage that causes brain cells to die. It is most common after the age of 65, but younger people can also get it. The main symptoms include impaired cognition (difficulty with abstract thinking, language, communication and memory) and difficulties managing everyday tasks such as shopping, driving, preparing meals and maintaining work or hobbies. Most people live with dementia for quite a long time and need varying levels of support and care.

Dementia also counts as a disability according to the definition of the United Nations Convention on the Rights of Persons with Disabilities. The convention adopts a social and human rights based approach to disability. It looks at disability not as something that is solely linked to a particular medical condition but as something that is also the result of how society is organised. This includes attitudes, practices, physical structures and procedures etc. Society therefore has a responsibility towards people with dementia. It must provide timely and appropriate support to enable people with dementia to participate in society and have the same opportunities as everyone else. This means making appropriate adjustments (known as ‘reasonable accommodations’) where necessary. All Member States of the European Union have signed this Convention so they have to do what it says. It doesn’t just apply to governments but to a wide range of people including those who provide services, care and support.

For you, as a health or social care worker, it means that you need to think how to do things so that people with dementia can enjoy their lives as far as possible like other people do. When determining what kind of adjustments are ‘reasonable’ to achieve this, there is a risk of focusing on the needs and wishes of the majority ethnic group and those of minority ethnic groups being overlooked, ignored or neglected. Making such adjustments is about treating everyone fairly and respecting the rights and dignity of every person as a human being.

How lay people understand dementia

People understand dementia and try to make sense of why it happens in different ways. Some of these ways are more common in certain cultures than in others. The words people use reflect and affect the way they think about things. Many different words are used to describe dementia. Some of them come from everyday language, others from the medical profession and their use changes over time. In English, for example, words like ‘senile’ and ‘demented’ used to be very common. They reflected a perceived link between dementia, old age and mental disorder. Today, these terms are less common and a lot of people, including people with dementia, find them offensive.

In some languages there is no word for dementia, at least not in everyday language. In most languages, there are everyday terms for dementia. Often these reflect being forgetful, obsessed or confused, having a mental disorder or having reverted to childhood. Some of these terms are euphemisms (i.e. replacement words for others that are considered offensive, harsh, unpleasant or inappropriate) but some suggest mockery or are clearly derogatory.

When trying to raise awareness about dementia and promote help seeking, it is important to understand that dementia can be perceived and experienced by people in very different ways. Different perceptions are not problematic in themselves or restricted to certain minority ethnic groups. However, in some ethnic groups, people do not see dementia as a medical condition at all. If they also lack access to culturally appropriate information that is understandable to them, they might miss out on medical and social care, treatment and support that other members of society are benefiting from.

In the remainder of this section, we look at some of the different ways that people make sense of dementia. Hopefully, this will help you to recognise and respect different perceptions and to frame or adapt your explanations so that they are also understandable and acceptable to people who have different perceptions of dementia.

A natural part of ageing

Many people, from all cultural groups, see dementia as a natural part of ageing. Even those who consider dementia as a medical condition may think that it is normal for older people to get it (like it is normal for older people to get wrinkles and grey hair). A member of the Pakistani community living in Norway described this way of understanding dementia as follows:



If a person throws stones at other decent people, or uses an iron bar to hit someone, then we think he is sick. But if he just talks nonsense or has lost his memory, we think it is probably because he is old. Then it's OK, and we have to take good care of him and behave as usual. (.../...) It's normal for old people to become weird and difficult" (Næs and Moen, 2015).

Considering typical symptoms of dementia as signs of normal ageing may lead to people accepting and tolerating certain behaviours. This can be a good thing in the sense of continuing to respect people with dementia and not see them as a problem. However, it can also mean not seeking outside help. This is especially likely in communities where the family is the central unit of importance and where there are strict cultural norms and traditions about how to respect and care for older relatives.

Mental disorder

It is quite common for lay people as well as health and social care professionals to consider dementia as a mental disorder. Diagnosis, treatment and support for people with dementia are organised in some countries under the umbrella of 'mental health services'. There is nothing wrong with terms like 'mental health' and 'mental condition'. However, people with mental health conditions have been discriminated against and treated badly. There are also numerous terms used to refer to people with mental disorders (e.g. mad, crazy, nuts and mental) that are derogatory and reinforce prejudice and discrimination. Perceiving dementia as a mental disorder may therefore interfere with help seeking. This is especially the case where mental illness is believed to be hereditary and where the honour of the family and even marriage prospects could be affected by the knowledge that a member of the family has a mental health condition.

"God's will" or caused by spirits

Some people, not just within minority ethnic communities, believe that dementia is due to fate, evil spirits or curses. They see it is a test or punishment from God for something they, or a member of their family, have done wrong. In religions where people believe in reincarnation and karma (the spiritual principle of cause and effect

whereby things happen to people because of their actions), this wrong-doing or fault may have occurred in a past life. Such beliefs may exist alongside the recognition of dementia as a medical condition. People may therefore sometimes seek help and support from healthcare professionals as well as religious/spiritual leaders or, depending on the importance of religion/spirituality in their lives, just from religious and spiritual leaders. This represents an obstacle to seeking a diagnosis and appropriate support and care. On the other hand, religion and spirituality can be a valuable source of social support and mental strength.

Heredity

The term 'heredity' means the transmission of genetic characteristics from parents to their children. 'Genetic' is a broader term linked to genes and the study of genes. Many people are worried that if a close family member has dementia, they will get it too. In some minority ethnic groups, the belief that dementia runs in families, combined with perceptions of dementia as a mental disorder and concerns about the honour of the family, can be a strong deterrent against help seeking.

Life events, other health conditions and isolation

Even when dementia is considered a medical condition, some people believe that it can be brought on by major life changes such as retiring, bereavement or moving home. Others link it to co-existing medical conditions or to social isolation, loneliness or neglect. Indeed, certain medical conditions and psycho-social factors may actually contribute towards the onset or further development of dementia. Moreover, where these factors are more common in certain ethnic groups, this might partly explain why there are higher number of people with dementia in those communities. In some minority ethnic groups, there is also a belief that dementia does not exist in their country of origin (or that of their ancestors). Possible explanations for this are that in some countries, people with dementia are cared for at home by relatives or dementia is not considered a medical condition, which means that dementia is less visible within the community where stigma may also be an issue.



- Provide people from different ethnic communities with culturally appropriate and understandable information about dementia and existing services and support.
- Make sure that people understand that dementia is a medical condition and that health and social care systems in Europe offer support and care to people with dementia and their families.
- Do not judge people for having a different understanding of dementia to your own but try to ensure that this does not result in people with dementia not getting the care and support they might need or benefit from.





Chapter 2. Different cultural approaches to dementia care

Dementia care as the family's responsibility

Different cultures may have different beliefs about the role of the family in people's lives. In some cultures, families have a central role in that social norms, personal attitudes and behaviours are defined, expressed and judged with the interests of the family at heart. This could be described as a 'we culture'. It is based on shared principles and values, which include showing respect to older people, obeying parents and taking mutual responsibility for each other. This is quite different to the individualism of the 'I culture', which is more common in majority ethnic groups in Europe, where the emphasis tends to be on principles and values reflecting personal autonomy, independence and the interests of the individual.

It is a common view in many European countries that people from minority ethnic groups 'look after their own' and do not want support. If you think this, you might not make as much effort to ensure that people know about services. This can make it difficult for some people to seek help and some people don't have children or other relatives to provide support or don't want to be supported by them. Cultural traditions surrounding care might sometimes clash with your own expectations and values. You might find it difficult to understand certain attitudes, needs, beliefs and behaviours that are common in some minority ethnic groups. You might find it difficult to accept gender divisions and feel frustrated when support and services are not taken up. This might even seem to confirm the belief that 'they look after their own' and don't want or need help. It is much more likely that such support and services are not culturally appropriate or sensitive, or that people don't know about them or that they are entitled to them. Another reason could be that people from some communities don't want to be seen as incapable or unwilling to care for their relatives.²

Religious and cultural beliefs about duty

Decisions about who is the spokesperson and who provides care are often based on religious beliefs and cultural traditions. In some religions and communities, families are considered obliged to take care of a person who is vulnerable, ill or disabled. Sometimes, this is linked to the belief that illness or disability happens to people who have done something wrong, and that they are being punished. This could be the person with dementia or one of their relatives. Another belief, as mentioned earlier, is that it is a test from God. Either way, relatives providing care, in most cases women, may want to show that they can pass the test or accept the punishment without complaining. Accepting outside help could be interpreted by the carers or members of their family as failure or a rejection of the test or punishment.

² See also sub-sections on "religious and cultural beliefs about duty" and on "pride, honour and shame".

Pride, honour and shame

Religious beliefs about children's respect and responsibility for their parents can sometimes be linked to the concepts of pride, honour and shame. Someone who does not provide care when needed may be considered as bringing shame on the family. In some cases, honour and shame have far-reaching consequences on the direct and extended family, irrespective of how close or far away they live. However, some people feel proud and have a sense of satisfaction from providing care and fulfilling their obligations. Religion and spirituality can be powerful sources of support and central to coping strategies for many carers.

Gender roles

In some ethnic communities, a male relative may be considered as the spokesperson and decision maker for the family. In such cases, he is the key contact person when it comes to asking for help and support. Actual care is usually provided by women with a few exceptions (e.g. for some intimate care of a male relative, reading prayers and dealing with transport). This is often linked to traditional gender roles and patriarchal values within communities, sometimes reinforced by religious doctrines. When the family is asked about possible support and services, the spokesperson may sometimes have little idea of the difficulties faced by the women with the hands-on responsibility for the provision of care. Some professional carers may find this difficult to accept but the focus must be on providing support and services that are culturally appropriate and not on trying to change people's beliefs and practices. The challenge is to find ways to provide support that is acceptable to all concerned.

Female carers are often reluctant to seek support for fear of being criticised for not being able or willing to provide care and of letting the family down. At the same time, many find it rewarding to provide care and to receive recognition and praise from their relatives and other members of the community. Some see their role as a sign of moral superiority. Others end up being the sole carer because they were the one involved in interpreting during initial care consultations. The challenge for you is to ensure that carers receive support if and when they need it and that they do not wait until a crisis occurs and they can no longer cope.

Within each family, there may also be different attitudes towards caring (e.g. between younger and older generations, between men and women), with people sometimes finding themselves caught between seemingly contradictory traditions, values and responsibilities. Some have found novel solutions such as sharing care whereby the person with dementia lives with different members of the family on a rotational basis. You may need to adapt the support and care you offer to these different ways of organising informal care.

Concerns about the quality of care

Many people believe that good quality care can only be provided at home by the family. People with dementia and their relatives from some minority ethnic groups worry, in addition, about the person with dementia not being understood, about care not being culturally appropriate and about not getting enough food or the kind of food that they are used to. The family is often considered as being more caring, providing greater security and knowing the person with dementia best. This is in stark contrast with a lot of media reports about the care that older people receive in residential or nursing homes. Indeed, living in a safe environment, surrounded by familiar caring people who speak the same language is clearly a solid basis for good care. However, it is not a guarantee of good care, especially if carers struggle without outside support if and when they need it.

Gratitude and repaying kindness

Regardless of religious beliefs and concepts such as pride, honour and shame, many people consider caring for a relative, especially a parent, as an opportunity to repay them for the care they received when they were younger. It is an expression of gratitude. For some, it is a moral duty. This differs from the attitude that is perhaps more common amongst majority ethnic groups in much of Europe, namely that people have a right to professional care and that governments have a responsibility to provide it.

Live-in migrant carers

Live-in migrant carers are people who live in a person's home and provide round-the-clock care and support. Many come from Eastern-Europe, Asia and Africa. They are often 'employed' to care for people with dementia from the majority ethnic group but live almost as a member of the family. Many have restricted residency rights, lack proper healthcare cover, work long hours for low pay and have limited time off. Some are taken on illegally and paid in cash. Many are not fluent in the language of the country, are socially isolated, do not have experience or training and are not familiar with the traditions and culture of the host country. This puts them at risk of abuse and exploitation, and is something that governments need to look into. Live-in migrant carers nevertheless provide valuable care and support to many people with dementia, enabling them to live in the comfort of their own homes and within their communities for longer. Although the boundary between professional and informal care is somewhat blurred, you may be in a position to support them in some way (e.g. by offering training or advice).

- Talk to the family spokesperson if there is one but also take up any opportunity offered to talk to the members of the family directly providing care.
- Don't lose sight of the person with dementia as a result of making an effort to include the family in discussions about care.
- Where appropriate, try to describe services as opportunities for carers to provide the kind of care they would like to provide, rather than as ways to relieve them of their responsibilities.
- Avoid inferring that professional care is better than informal care.
- Not everyone in a particular ethnic group shares the same values about care or even has a family. Don't forget that many people with dementia need and will accept support themselves.
- Ask what kind of support or services would be helpful. Consider adapting the kind of support available and, if necessary, develop new innovative approaches that reflect the needs and wishes of people from different ethnic communities.





Chapter 3. Intercultural care and support



Most people with dementia will need or would benefit from professional support and care at some point in their lives. It is widely accepted that care and support for people with dementia should be person-centred. This means the provision of services that are adapted to the needs and wishes of each person with dementia. These will usually be linked, to some extent, to their cultural, religious and linguistic backgrounds. A person-centred approach means that every person is considered unique, is valued and is treated with respect and dignity. As most people live within family networks and communities, such care and support should also extend to their relatives, close friends and members of the communities in which they live.

Person-centred care and support for people from all ethnic groups requires a proactive, intercultural approach in which cultural diversity is not only accepted but also promoted through the development of:

- cultural awareness (knowledge and understanding of differences between oneself and people from other countries and backgrounds),
- cultural sensitivity (acknowledging cultural differences and similarities without judging),
- cultural competence (combining such knowledge with appropriate attitudes and skills).

There are so many different cultures and sub-cultures within Europe that you couldn't possibly be expected to know about them all (i.e. about their shared history, traditions, languages, religions, values and beliefs). Moreover, members of one ethnic group are not necessarily familiar with the traditions and religions of other ethnic groups. Developing awareness, sensitivity and competence takes time. Mistakes will happen and this is part of the learning process. It is important to take an interest in people from other communities and to ask questions. The questions would obviously depend on the situation and the ongoing conversation or interaction but might, for example, be something like:

- What kind of food do you miss most since coming to live here?
- Is there anything I can do to help you celebrate Ramadan?
- What is the main celebration/festival in your religion?
- In the Vietnamese community, what do people usually offer guests to make them feel welcome?
- When I arrive, you always say 'As-salāmu alaykum'. What does it actually mean and what should I normally say back?
- What is the reason for people taking off their shoes when they enter someone's home?
- I noticed you chatting to Mr Brøgger this morning and I was surprised as you seemed to be speaking different languages? How do you manage to understand each other?
- How do you say 'sleep well' in Sami?

This will normally be seen in a positive light, as genuine interest, and not as being nosy or drawing attention to your lack of knowledge. The aim is for you to get to know your clients and to ensure that the care or support you provide is in keeping with their needs, hopes and expectations.

Appearance, clothing and accessories

Our appearance, clothes and various accessories communicate something about who we are. Clothing may also contribute towards the feeling of independence and of belonging. At a practical level, people like to wear clothes that they feel comfortable in and at ease wearing, both psychologically and physically. Clothes can also reflect geographical, historical, cultural and gender norms. In some cultures, there are traditions linked to hygiene and religion that require people to carry or wear certain accessories or to wear specific garments that cover the head or body. There can be subtle differences in the way clothes like saris and turbans are worn by people from different ethnic communities. It is important that people with dementia are free to dress as they please and to have help if needed to obtain and to wear the clothes and accessories they prefer.



- Don't underestimate the importance of people's freedom to choose what to wear.
- If people with dementia need assistance dressing and you don't know how certain garments should be worn, find out as it is likely to be important for them and perhaps also for how they are perceived by others.

Religious duties and activities

Religion can be an important part of a person's life. People with dementia may want to continue to practice their religion by praying alone or with others, or by participating in various religious activities and ceremonies (e.g. Christians celebrating Christmas, Muslims practising Ramadan or Jews celebrating Passover). Therefore, certain times and dates may be less appropriate for care assessments or to receive certain services but efforts to mark certain special events (e.g. by having celebrations in care homes and special meals) could be particularly appreciated. People may also appreciate transport or to be accompanied to places of prayer (e.g. to synagogues, temples and churches). Fellow members of the relevant religious communities might be able to help. In some religions, it is common to have a special place for prayer in the home.

- Check with people with dementia if they have spiritual or religious beliefs and if so, whether they would like any support to continue worshipping or being involved in a particular spiritual or religious community.
- Discuss possible difficulties (only with the permission of the person with dementia) with a leader from the relevant spiritual or religious community to see what kind of support might be needed and whether members of that community could help.



Hospitality

Health and social care workers who go into people's homes should have at least a basic understanding of different traditions (e.g. linked to gender roles, different ways to greet people, taking shoes off when entering a person's home, sitting on the floor correctly, finishing what is on your plate, accepting a second cup of tea). In many cultures, the offer of food and drink is an important sign of hospitality, which may explain why people sometimes insist when the offer is initially declined. Refusing offers of hospitality in a way that is culturally appropriate is therefore also important.

Food and drink

Food can be a source of pleasure. Familiar food can have an impact on people's quality of life, sometimes also providing a structure to the day and an opportunity to socialise. As mentioned above, it is often a sign of hospitality and welcome. Food traditions (including restrictions) are sometimes influenced by religious beliefs. In both Islam and Judaism, for example, it is forbidden to eat pork. Most Hindus are vegetarian, and most Sikhs will eat meat but not Halal meat. In some religions, there are periods of fasting, the most well-known perhaps being during Ramadan in the Islamic faith, which involves fasting for 30 days from sunrise to sunset. Religious dietary requirements may vary geographically and change over time (e.g. the Christian practice of Friday fasting). It is important to find out what people are used to eating, what they enjoy and what they need to eat or avoid in order to fulfil religious obligations.

Getting to know people with dementia from different cultures

People from minority ethnic groups, like everyone else, would like to live in an environment in which they feel safe, happy and respected. This should also include the opportunity to listen to music or the radio, watch TV and read newspapers or books in their native language. Communication is fundamental to creating relationships and providing a sense of security. It is important to know about key events in a person's life. Conversations about events from the past, however, can sometimes bring back traumatic memories and emotions (e.g. of war, abuse, loss and illness). Health and social care workers need to be sensitive to signs of distress. Often, it is enough to be present, empathetic and supportive, but sometimes help may be needed from more experienced professionals to help someone deal with or work through certain emotions. Life stories and information from relatives may also help professional carers to get to know people with dementia better. Pictures and music from the past may help but should be culturally appropriate. Talking about the present and about things going on in the news and the community is also important.



- Try to find out about the traditions, key historical events and festivals, and key values often shared by people from different cultural groups.
- Show respect and recognition of individuals and their culture.
- Get to know what is important, enjoyable and meaningful to people in their everyday lives (e.g. activities, food, clothing, social interaction and praying).
- If unsure about religious or cultural traditions or dietary requirements, just ask. In most cases, this would be seen as an expression of respect and genuine interest.







Chapter 4. Language and Communication

People use language and communication to convey their thoughts, desires and needs, and to maintain social relationships. Good verbal and non-verbal communication is crucial when dealing with the practical and social aspects of everyday life. Social interaction is key to good quality care and support. Language difficulties are a common symptom of dementia. For people who acquire a language later in life (e.g. after having moved to Europe), this can be a further challenge because the last language to learn is usually the first to be affected. A person's mother tongue is usually retained longer, but this will often be a language that you don't understand or speak. It is important for people with dementia to have the opportunity to communicate in their own language. Language barriers can therefore be a major challenge when trying to provide intercultural care and support. Such barriers can also lead to social isolation and loneliness. In some cases, language difficulties make a person's dementia look worse than it actually is.

The importance of a multilingual workforce

People often like to receive support and care in an environment that reflects their culture, traditions and religion, and where most, if not all, health and social care workers, as well as support staff, speak their language. An example would be a day care centre for people from the Polish community where the staff speak Polish, are familiar with Polish traditions, including religious obligations linked to the Roman-Catholic Church and serve Polish food. It is important to ensure that people with dementia all have some access to professional carers who speak their language.

Some service providers try to match professional carers with people with dementia from the same community who speak or understand the same language. This can provide people with dementia with a sense of security, promote wellbeing and enhance quality of life. However, some people who speak the same language might appear to be from the same ethnic group when this is not actually the case. They may even be from groups with a history of political conflict and with different religions or dialects. In some communities, there are also strict social hierarchies and caste systems that may affect preferences. In addition, some people may have concerns about confidentiality and privacy because in close knit communities, everyone knows everyone else.



- Check with the people with dementia and their families what they prefer.
- Try to avoid making assumptions about what people from one ethnic group do and do not have in common with people from another ethnic group. If in doubt, check.

Verbal communication

Not everyone from a minority ethnic group speaks a different language or has lost the use of an acquired language. However, within some communities, there may be subtle differences in language use (e.g. different ways to express emotions, to speak to older people, to express friendliness or respect, or to talk about parts of the body etc.). This is not always obvious but of huge importance when it comes to providing respectful and good quality care and support.

Language use is not always an all or nothing matter. Many people who have lived all their lives in a particular country are able to speak and understand the national language but not perfectly. This can become particularly problematic for them when this is combined with language impairments that are common with dementia. Within some ethnic communities, women do not traditionally have paid jobs and therefore lack the same opportunities that men have to use the national language in the workplace. In addition, they are more likely to use a different, common language amongst themselves and to socialise mainly with people from the same minority ethnic group. This makes it difficult for them to become proficient in the national language.

- Give people enough time to express themselves.
- Wait, even if there are long breaks, and pay attention to subtle, non-verbal signals.
- Make tentative suggestions if the person is still looking for words.
- Rephrase to check what was said and whether it was correctly understood.
- If unsure, ask the person to repeat what you have explained “so that you can check that you have explained things properly”.
- Show understanding and empathy when someone has difficulty trying to explain something. It can be frustrating and embarrassing for them.
- Use short statements with common words that are easy to remember and understand.
- Break up complex information into smaller chunks.
- Talk slowly and clearly, without exaggerating (to avoid people feeling like they are being treated like a child).



Even if you don't speak the language of your clients and are not good at languages, you can probably learn a few words and phrases. Doing this demonstrates positive curiosity and interest, and shows that you value the person's culture. It may also be reassuring when someone is stressed, anxious or frustrated. People are likely to feel respected and accepted if they are addressed in the appropriate manner. It is sometimes more important how you say something than what you say.



- Learn some common words, phrases or snippets of songs in the person's mother tongue (either from the person with dementia, relatives or colleagues).
- Ask interpreters and family members about words and expressions (e.g. thank you, please, good morning, would you like some tea? enjoy your meal, sleep well etc.).
- Use other common languages (a lot of people speak or understand some English).
- Speak to the person anyway (because your tone of voice may be reassuring, it can be perceived as social contact and it can help people feel less isolated).
- Pay attention to various forms of non-verbal communication (see next sub-section).
- Find out how the person with dementia and their relatives would like to be addressed and try to pronounce their names correctly.

Non-verbal communication

It is important to pay attention to non-verbal communication because difficulties understanding and speaking are common amongst people with dementia from all ethnic groups. Non-verbal communication covers a variety of means other than words to convey information, either intentionally or without realising it. This can include:

- gestures and movements (e.g. nodding, shaking or lowering the head, slouching, specific movement of hands, arms and head or tapping of the feet or fingers),
- facial expressions (movement of eyes, eyebrows, nose, forehead and mouth),
- eye contact,
- physical distance or closeness,
- noises (e.g. tutting, sighing or humming),
- tone of voice,
- physical touch, and
- offers of food and drink, or to take a seat.

To some extent, appearance (e.g. hair, clothes and makeup) can also be a form of communication. Whilst it is important not to judge or jump to conclusions about someone on the basis of their appearance, a gradual or sudden change might reflect an emotional state. Non-verbal communication is not a precise science. It can help people to understand each other better but there are few hard and fast rules for interpretation, and there may be some cultural differences (e.g. whether direct eye contact is considered rude, arrogant or a sign of respect).

- Be attentive to the non-verbal communication of people with dementia (irrespective of their language ability).
- Try to be aware of your own non-verbal communication and use it in a positive way.

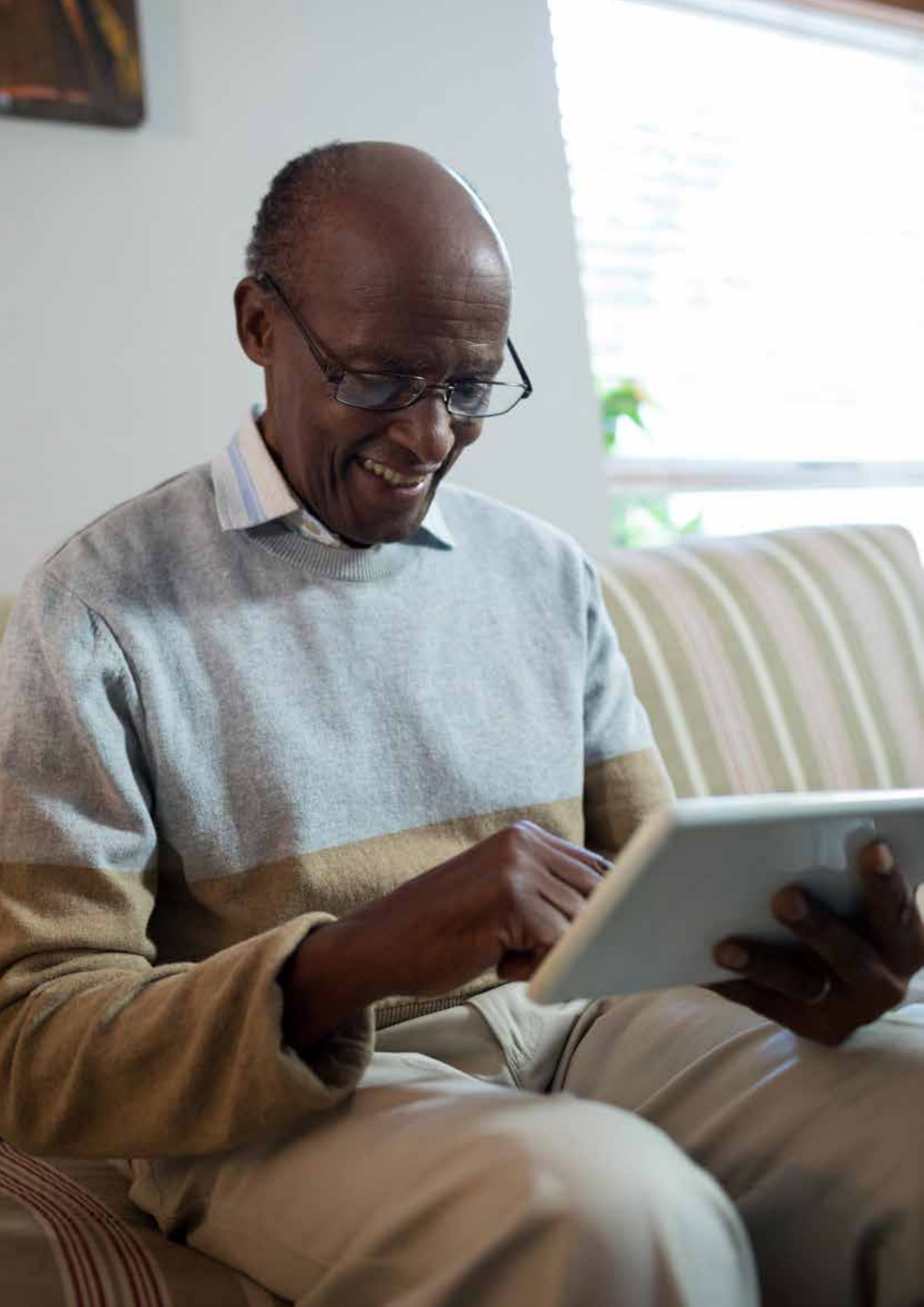


Interpretation

It is important to involve professional interpreters in discussions about health status, treatment and the provision of services. For discussions about everyday activities, it may often be sufficient to involve multilingual staff. Relatives can also sometimes provide interpretation, and this may contribute towards a sense of security. Some people with dementia might prefer to use a friend or relative to interpret. If that is not allowed where you work, it is important to explain why (e.g. that the person might be biased or misinterpret a question or response and that your organisation can't take that risk). Some people might not feel comfortable acting as an interpreter. They may find it stressful or that it conflicts with their role of informal carer or their relationship with the person with dementia. Young adult children may sometimes feel uneasy about some of the topics discussed, feel under pressure and worry about the consequences of making a mistake. Efforts to understand people with dementia who are not fluent in the national language are amongst the reasonable adjustments that must be made to ensure that people with dementia from minority ethnic groups have the same quality of care and opportunities as people from other ethnic groups.

- Seek a professional interpreter for discussions about health status, treatment and the provision of services, as well as for any issue that may have a significant impact on the life of the person with dementia.
- There are hundreds of languages and dialects so make sure you get an interpreter who really can understand and speak to the person with dementia.
- Try to work together with your colleagues and with the relatives and visitors of the person with dementia to communicate with him or her about daily activities.
- Gradually build up the ability to communicate directly, as far as possible, with the person with dementia.
- For the reasons mentioned above, be attentive to the possible reluctance of the person's friends and family to act as informal interpreters and, except for informal social exchanges, do not ask children to serve as interpreters





Chapter 5. Collaboration with families



Not everyone has a family or children and some people live alone, are not on good terms with their relatives or prefer to manage independently. But in many minority ethnic groups, the broader family plays a central role in providing care and support. Consequently, where there is a family, their needs, views and perspectives can be particularly important as they may have a considerable impact on the care and support that people with dementia receive at home, as well as on whether people with dementia have access to professional support and care. Such involvement does not replace the need to try to involve people with dementia directly in the organisation and planning of any care and support they may need.

Working together to develop better intercultural services

As mentioned earlier, there may be cultural expectations and pressure on people from some minority ethnic groups to care for their relatives at home. This does not mean that everyone from those groups is willing or able to do so. Relatives of people with dementia from minority ethnic groups vary in their responses to providing care and accepting outside help. At the same time, in most countries there is a lack of intercultural care and support. People with dementia and their families can play an important role in helping develop and improve services and support. They have valuable experience and knowledge about their culture. They can provide constructive feedback about how to make existing services and support more culturally appropriate and how to develop new services that would better correspond to the needs and wishes of people from minority ethnic groups and hence be more likely to be taken up.

Involving relatives in everyday care

Relatives can be important collaborative partners for health and social care workers as they have knowledge about the individual's life, preferences, needs, history and local environment, and speak the same language or dialect. Their presence may also provide a sense of familiarity and trust. Their advice could be particularly helpful during crises or difficult care situations, and their support important for people with dementia who find themselves in an unfamiliar environment amongst people who do not dress the same, speak the same language or eat the same food. Relatives can help raise awareness of linguistic and cultural differences and act as mediators between their relative with dementia and health and social care workers. In fact, they play an important role in the provision of culturally sensitive care by informing professionals, and by personally offering care or speaking to the person with dementia in their own language.

In many cases, families are keen to be involved in care (e.g. bringing in food, taking over certain care tasks and providing company), even when health and social care professionals are providing services. This can be mutually beneficial if responsibilities, roles and limits are clearly defined and if this can be achieved in a positive way (e.g.

not perceiving it as critical, interfering or judgemental). It can be a valuable source of support when people with dementia have recently moved into a residential care home or are in hospital and health and social care workers have not yet had the chance to get to know them, are not fluent in their language or are unfamiliar with their cultural background. Some of these challenges may persist in the long run but such support from families should only supplement formal/professional care and not dispense with the need for staff to acquire cultural competence. People with dementia need to feel safe and valued at all times, not just when their relatives are present.

The role that families can play in the provision of care to people with dementia in residential care settings needs to be sensitively negotiated at the start because families and professional carers from different cultures may have different taken-for-granted assumptions about what is normal, what constitutes good care and the role of each in providing it. Great sensitivity is needed to try to ensure that solutions provide some recognition of the families' views and traditions linked to caring. This will help ensure that their contributions to the provision of intercultural care are perceived as valuable.



- Try to be proactive in offering support and avoid making assumptions about what families do and don't want.
- Bear in mind that relatives are not neutral professional interpreters and have their own needs and interests, as well as a particular relationship to the person receiving care.
- Try to think about adjustments that could be made to demonstrate acceptance of culturally appropriate approaches to care.
- Avoid discussions turning into issues about winning or losing.







Chapter 6. Summary and take-home messages

People from the same ethnic community typically share similar values, have common traditions, and in many cases a shared religion and language. All these things are constantly evolving within families and ethnic communities. Different values and practices may also occur alongside these. Nevertheless, there is a risk of over-emphasising difference and of stereotyping, which could jeopardise the provision of truly person-centred care. Awareness and acceptance of cultural differences does not need to overshadow recognition of the many things that people from all ethnic groups have in common. It can and should provide a solid basis from which to explore the needs and wishes of each person.

The provision of intercultural care and support requires cultural awareness, sensitivity and competence. This is not something that can be learnt solely from a book. It is an ongoing process of learning and exchange. No one is expected to understand the traditions, values and beliefs of people from other cultures straight away.

In some minority ethnic communities, families prefer to provide care themselves and outside support is not always viewed favourably. However, families should still be offered support and may benefit from it. It is necessary to take into account concerns they may have and cultural and religious expectations surrounding the provision of care, sometimes also influenced by beliefs about the cause of dementia that are not conducive to seeking help from health and social care professionals.

If you identify with a minority ethnic group, you might be able to provide valuable support and help your colleagues to acquire cultural competence. However, your professional skills and career advancement should not be limited to providing care to people from a specific ethnic group. Similarly, it should not be assumed that because you are from one minority ethnic group, you necessarily understand the needs and wishes of everyone from that group or from other groups.

Information about dementia and available support needs to be provided in a culturally sensitive form, style and manner. It should reflect or acknowledge different ways of making sense of dementia and different attitudes towards care.

Finally, every person with dementia is unique. Although people with dementia may share some characteristics with other people from a particular ethnic group, it is important not to lose sight of the individual.

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