As part of its Dignity on the Ward campaign, Help the Aged commissioned a series of pocket guides that began with Working with Hospital Patients with Dementia or Confusion. Other titles in the series include Promoting Dignity in Hospital, Pain and Older People and Bereavement and Loss, as well as this title, Working with Older People from Ethnic Minorities.

We hope that this guide will help hospital staff to understand better the needs of vulnerable older patients and their families and perhaps to appreciate more fully the importance of taking a person-centred approach.

Fighting for disadvantaged older people in the UK and overseas,

**WE WILL:**

- **COMBAT POVERTY**, wherever older people’s lives are blighted by lack of money, and cut the number of preventable deaths from hunger, cold and disease
- **REDUCE ISOLATION**, so that older people no longer feel confined to their own home, forgotten or cut off from society
- **CHALLENGE NEGLECT**, to ensure that older people do not suffer inadequate health and social care, or the threat of abuse
- **DEFEAT AGEISM**, to ensure that older people are not ignored or denied the dignity and equality that are theirs by right
- **PREVENT FUTURE DEPRIVATION**, by improving prospects for employment, health and well-being so that dependence in later life is reduced
**Background to the project**

This pocket guide was developed for Help the Aged by members of the Policy Research Institute on Ageing and Ethnicity (PRIAE)

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as part of a project commissioned by the Help the Aged Dignity on the Ward campaign.

**Note** This guide does not cover the clinical treatment of patients.

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Introduction

This guide aims to provide information and ideas that will help you and your multidisciplinary team respond to the different needs of minority ethnic elders. The National Service Framework for Older People (2001), National Service Framework for Older People in Wales (2006) and the Race Relations (Amendment) Act (2000) aim to improve services for minority ethnic elders and to eradicate discrimination. However, there is increasing evidence that ethnicity is a factor in social and health inequalities among older people.

Such inequalities are the result of the complex interaction of genetic factors, environment, lifestyle, health-seeking behaviours and service provision. Greater knowledge and understanding of the specific needs of different minority ethnic elders will help to reduce inequalities in care and improve patient outcomes.

This guide will:

1. show you how ethnic, cultural and religious difference can affect the hospital experiences and care needs of minority ethnic elders and carers
2. provide information and guidance to help you better understand and respond to the needs and choices of minority ethnic elders
3. show what culturally responsive care might look like and identify barriers to dignity in care for minority ethnic elders
4. help you to examine the extent to which you are meeting the specific care needs and preferences of different minority ethnic elders.

Many of the ideas for helping to promote dignity for minority ethnic elders would help protect the dignity of anyone, regardless of ethnic background.

‘Old age means dignity. Having good friends, having peace of mind, also the ability to contribute to the community.’ (M.A. Khan Lodhi, speaking in the 2007 PRIAE film Progressing Policy with Passion)

‘Losing dignity is not something that only happens with poor exchange with some professionals or other patients. If you are independent and mentally alert, being in the hospital, bed-bound and being unable to go to the toilet [by] yourself is enough to lose your dignity. Imagine that. How you then cope, adapt and regain your self-worth and hope becomes a big challenge. Add staff (and they can be from both minority and majority backgrounds) who do not understand your loss of self-worth, or who neglect you, and it is then not that far to reach the bottom.’ (Mrs Shantaben, PRIAE Elder Volunteer, speaking to PRIAE staff while in hospital in 2007)

‘At the moment it can be difficult because we’re dealing with different generations. I remember a very large Muslim family who had a number of generations within the household. The younger generations were pushing for more active treatment and had more understanding about medications and understood decisions that were being made and wanted to take part in those decisions and wanted information, but at the other end of the line were orthodox Muslim elders who said, “It’s in God’s hands. Nothing to do with us”, and they didn’t really understand the nursing role either; and what that was all about. So we were trying to manage all of this in one family and it was really difficult. I very rarely actually got to the patient. I was speaking with the layers of family.’ (nurse)

‘The onus is on all professionals to constantly reflect on what we are doing, listening to what patients need, rather than doing what it is convenient for us to provide.’ (doctor)
Minority ethnic elders and dignity

In 2007 Help the Aged carried out work to review the meaning of dignity in care and how services could be assessed in practising it. Nine key areas of care were identified where dignity is a fundamental requirement: personal hygiene, eating and nutrition, privacy, communication, pain, autonomy and choice, personal care, end of life, and social inclusion. ‘Your aim as a health professional should be to ensure that an older patient’s ethnicity never becomes an excuse for paying less attention to their right to dignity, and to the flexible, person-centred care that lies at the heart of it.

What is it like for elders from minority ethnic communities to be in hospital?

“When I was in hospital after my first heart attack the nurses were not very kind. Maybe they were too busy, but if I asked for something I wouldn’t get it. If I asked them for an extra pillow to raise my head, they would say “You’re not the only patient here.” They did not like the smell of the oils that I was using and I had to keep asking for a jug of water to wash before my prayers. No one remembered.”

What is it like to be in hospital when you don’t speak English?

“Because I don’t speak English I didn’t understand what was happening. They would ask me to take off my clothes and put on the hospital gown and they would take x-rays of my chest but I didn’t know why or what for. Once the x-ray was done, I would leave the room and would not understand why they had taken the x-ray.”
You have to have the will to survive. I did not like the food. Sometimes I had cheese but I do not like cheese, and with the language barrier I did not know how to say it. I had to eat it, because if I did not eat I would lose more weight. I think we have to have the will and be stronger when we are in a hospital, eat your meal and do the right thing, accept the advice, do everything right, and if you do it this way it helps a lot.

As well as being aware that some of you minority ethnic elder patients may not understand English, it is important to realise that many older people from ethnic minorities do speak English, and should not be excluded — for example, if the hospital chaplain or radio staff are going round the wards chatting to patients — on the supposition that they do not.

In trying to understand what dignity means to minority ethnic elders, you may find it useful to try to imagine how you would feel being a patient in a hospital in another country. What would be important to you? What would help you to communicate with staff if you didn’t speak the language? How might your inability to communicate affect your expectations and care choices? What fears might you have about your relationships with care staff? What might you do to try to be seen as a ‘good’ patient? Examine your own cultural values and attitudes and think about how these might influence you as a practitioner.

Discuss these issues in your team and think about what you can do to make patients feel more confident about expressing their needs and also dissatisfaction with care. Remember, a part of the ‘dignity challenge’ is ensuring that people feel able to complain without fear of retribution.

What is ‘good’ hospital care for minority ethnic elders?
- ‘Being treated like I was somebody’
- ‘A cheerful, friendly atmosphere’
- Good nursing care
- A clean environment
- ‘Having some control over my stay’
- ‘Doctors who take the time to explain things’
- Staff who came from a similar background
- Good post-operative care.

Providing culturally responsive care

‘An elderly Bosnian woman being admitted with terminal cancer may present the following challenges for health care staff and organisations: she and her family do not read, speak or understand English; her Muslim faith requires modesty during physical examinations; and her family may have cultural reasons for not discussing end-of-life concerns or her impending death. A culturally and linguistically appropriate response could include interpreter staff; translated written materials; sensitive discussions about treatment consent and advance directive forms; clinical and support staff who know to ask about and negotiate cultural issues; appropriate food choices; and other measures. The provision of these kinds of services has the potential to improve patient outcomes and the efficiency and cost-effectiveness of health care delivery.’

(The Office of Minority Health, USA)
**What is culturally 'appropriate', ‘sensitive’, ‘competent’, ‘responsive’ care?**

‘Cultural competence’, ‘sensitivity’ and ‘appropriateness’ are just some of the different terms that are being used to describe care that recognises and responds to differences in the care needs and preferences of people from minority ethnic groups. Such care can involve the provision of practical services such as interpretation and advocacy. It can also involve more focused communication and exploration in which attention to cultural/religious needs is a part of wider processes of assessment and care planning. Research has shown that patient outcomes can improve when a patient’s cultural, emotional, and personal concerns are considered alongside their medical condition. The better you understand a patient, the better the care you will be able to give.

I think there are quite basic things that can help you work sensitively with people from different cultures. It’s about respect and building up a relationship with patients and families – finding out about people and getting to know them.’ (nurse)

While it is impossible to predict the ways in which cultural and religious identity can affect the needs of patients, culture can affect beliefs about health, illness, treatments, healing and care. The following questions can help you explore and think about the different needs of minority ethnic elders:

**Beliefs about illness** How is the patient’s understanding of their illness influenced by cultural/religious beliefs? For example, cultural beliefs can affect attitudes to pain, emotional expression and notions relating to the cause of an illness.

How might such beliefs affect care and treatment choices?

**Example** For some Hindus and Sikhs, illness can be understood as a result of a person’s karma – previous actions and thoughts, and perhaps as a form of punishment for wrong-doings. Beliefs of this kind may lead to feelings of guilt or shame about an illness, or simply that it is the will of God and should be accepted as such.

**The body** How might the site of the illness/disease and its treatment affect the patient’s identity and daily practices?

Does the patient have any preferences for the provision of physical care and/or for safeguarding modesty?

The site of a disease, such as breast or prostate disease, can affect a patient’s sense of themselves as a man or woman. Some patients may not wish to be naked in front of professionals but prefer to keep some clothing on – for example, during examination or washing. Can you identify any other ways in which the culture/religion of the groups that you care for can affect bodily care?

**Food** What does the patient usually eat and drink? Are there any foods that the patient cannot eat? If the food brought is inappropriate, some patients may be reluctant, or unable, to bring this to the attention of staff. Will there be any religious festivals during the patient’s stay which involve diet (e.g., such as fasting or eating particular foods)?

**Religion/faith** In what ways is the patient’s religion/faith a part of their daily life? Has the patient’s illness had an impact on any of their religious practices or beliefs?
Example  For some patients a colostomy bag can seem to be at odds with rituals of cleansing before prayer. Guidance from a spiritual leader or chaplain can be helpful to patients in such cases. Have you made any provision in your institution/ward to enable patients to practise their religion? Do you have a list of faith-based organisations in your area so that you can call in an appropriate local spiritual leader when necessary?

Social context  How might previous experiences of social exclusion, poverty, trauma or racism affect experiences of illness and care?

Example  When people are ill and feeling vulnerable they may remember or try to make sense of past experiences. In the case of negative experiences this can be a part of the emotional and spiritual pain of illness. Listening to patients’ stories and/or support from a trained counsellor can be valuable to patients.

Remember, culturally responsive care is about the quality of your relationship with a patient.
Ethnicity, culture and old age

According to the 2001 census 7.6 per cent of the population in the UK is from a minority ethnic group. The size of different minority ethnic groups can differ: for example, people from South Asian backgrounds make up about half of the total of minority ethnic groups in the UK, while Chinese people account for about 5 per cent. The rate at which minority groups are ageing can also vary. In general, minority ethnic groups in the UK have a younger age profile. At present, among minority ethnic groups, Black Caribbean, Indian and Chinese groups have greater numbers of older people. The ageing of different groups reflects their patterns of migration and fertility.

Minority ethnic groups in Britain

Ethnicity is the term used to refer to shared cultural, religious and/or geographical identity. Everyone has ethnicity.

Culture is more fluid and refers to a shared way of life, including the rules, values, beliefs and meanings that can guide lifestyles and how people see the world.

Remember that ‘ethnicity’ and ‘culture’ do not by themselves provide you with any reliable information about a patient’s unique care needs. They are a part of a complex web of factors that can shape identity and lifestyle.

Minority ethnic elders: did you know?

- In 2001, 3.5 per cent of the population of Great Britain aged 50 and over were from minority ethnic groups.
- Minority ethnic elders often live with several different health conditions (co-morbidity). Also, they can be poor (see below), socially marginalised and have low expectations of services.
- The most prevalent life-limiting diseases among minority ethnic elders are coronary heart disease and cardiovascular conditions; other common chronic conditions are diabetes, arthritis/rheumatism, lung/breathing problems, osteoporosis and kidney problems.
- Elders from Bangladeshi and Pakistani groups are more likely than others to have a limiting long-term illness.
- Levels of awareness of mental health conditions such as depression and dementia are lower in minority ethnic communities.
- Many minority ethnic elders have low incomes, with approximately 40 per cent in the UK receiving social benefits or allowances. Overall, those from minority ethnic groups have higher rates of unemployment than their White British counterparts.
- Approximately 36 per cent of South Asian elders and 82 per cent of Chinese and Vietnamese elders do not speak English (UK MEC Study 2005).
- A significant problem for minority ethnic elders is the lack of information about services and the availability of information in their own language.
- Having places to worship and feeling able to talk freely about religious practices and needs are important aspects of health and social care for many minority ethnic elders.
In order to provide personalised care to minority ethnic elders, you need, ideally, to get to know each patient as an individual, and to find out about how ethnicity, culture and religion have meaning in their life. These meanings can vary between different generations, between the sexes and within the same family. This is why some researchers have defined cultural competence as a practitioner’s ability to respect and respond to each person as an individual.

If you have any doubts about the cultural and/or religious needs of a patient, ask them. Most patients and carers will be happy to talk to you.

**Communication – the foundation of dignity**

Good communication is central to care that is culturally responsive and that respects people’s dignity. Many minority ethnic elders feel that health care professionals do not listen to them or take their concerns seriously.

Good communication includes:

- providing the right environment – making time so that the patient does not feel rushed; providing some privacy when talking about sensitive and important issues
- ensuring the patient has any communication aids that they need e.g. a hearing aid, when you are talking to them
- taking account of both what patients say and how they say it (e.g. tone and body language – however, remember that body language can vary across cultures)
- using professional interpreters or advocates to talk to patients who do not speak English
- giving patients regular information about their condition and care so that they feel involved and can participate in decisions.

Different cultures have different approaches to health information. In some countries it is not normal practice for health professionals to communicate with patients and the concept of patients participating in decision-making on healthcare issues is unknown. In some cultures it is not the custom to ask for or wish for health information, so health professionals could easily assume that patients know what is happening to them when they don’t.

A related problem for some older people can be that they have received little or no education, and therefore have little understanding of physiology – how the body is made up and how it works. This, compounded by the barriers of language and of racial, cultural and religious issues, can make communication difficult. In some communities it is taboo to talk about certain subjects – sexual organs, or cancer, for example. Older women from these communities will not want men to be present during such discussions – and vice versa. Such sensitivities should be respected, but a partner or other close family member may still need to be briefed on, for example, the need for screening or the nature of the proposed treatment or care.
When I was working with elderly people from ethnic minorities, I often encountered challenges in communication. It is important to use a professional interpreter for the initial assessment. During this assessment, it is crucial to ensure that the patient understands that the interpreter is a professional and that information will be kept confidential. When using professional interpreters, it is advisable to explain the patient's situation beforehand and to tell the interpreter whether the session will involve any difficult or sensitive issues such as breaking bad news.

Try to have regular discussions with interpreters to review the communication process. Avoid using family members as interpreters, unless this is the patient's preference. Never use children or young people to interpret. Make sure that the patient's need for an interpreter, the language and dialect that they speak, and the telephone number of an interpreting service are recorded in the patient's records.

There are several different approaches to cross-cultural communication. The 'L-E-A-R-N' model is one popular example:

- Listen with sympathy and understanding to the patient's perception of the problem
- Explain your perceptions of the problem
- Acknowledge and discuss the differences and similarities
- Recommend treatment
- Negotiate agreement

'I think having that time to do a very in-depth assessment is vital because that will give us the background to work with that family later on.' (nurse)

When following the L-E-A-R-N model or in communicating with patients about their illness and care, some of the following questions may help:

1. What do you think caused your problem?
2. Why do you think it started when it did?
3. What does your illness do to you? What do you think is happening to your body?
4. How much does your illness affect your daily life?
5. How long have you been ill?
6. What problems has your illness caused you?
7. Is there anything about your illness that worries or frightens you?
8. What other treatments have your friends/family/others told you about for this condition?
9. What are the most important results that you hope to see?
10. Whom do you wish to include from your family and friends in discussions about your care and treatment?
11. With whom should we share information about you?
Common barriers to dignity in the care of minority ethnic elders

“You have to be careful that you don’t put everything down to culture because the situations are incredibly complex. I would actually ask the patient, because I would prefer to get their version of their culture. You may think you know what that culture or that religion generally do, but I still think it’s an individual thing.” (nurse)

- **Presumptions and stereotypes** – remember, only some aspects of a patient’s ethnicity, culture and/or religion will be relevant to their illness and care. Try to recognise differences within the same cultural/religious groups – and be open to surprises.
- **Poor communication** can lead to patients feeling anxious, isolated and that they are not important. It can also cause delays in diagnosis, the underassessment of need and inadequate treatment, including pain and symptom control.
- **Inflexibility** Patient needs change during an illness. For example, when patients are very ill they may choose to be less independent and have others make decisions for them. Recognise and enable changes that reflect patients’ varying needs.
- **Denial of difference** Good-quality care recognises and responds to difference, ‘treating everyone the same’ can lead to inequalities in care.
- **Fear and anxiety** – anxiety about causing offence or of working in new ways can be intimidating for professionals. Be aware of how you respond to patients when you are anxious or uncertain.
- **Lack of time** Responding to differences in patient need can take time. For example, it takes time to build up trust and an interpreted conversation can take up to three times as long as one in English/Welsh. If you cannot provide the time needed for such care, report this to your line manager.

Key supports to dignity for minority ethnic elders

- Find out as much as you can about the cultural and religious beliefs and practices of the older person you are caring for.
- Make sure that specific cultural/religious requirements are detailed in the care plan and recorded in notes so that they can be monitored and reviewed.
- Ensure that the patient and their family have all the information they need, in an appropriate format. Try to be aware of family dynamics, too – sometimes, under cover of culture and religion, families may try to deny the patient access to information.
- If essential information printed in the right language is not available, or the patient cannot read it, consider using other media such as an audio-recording in the patient’s own language. It is particularly important to explain the treatment where patient consent is required for a clinical procedure. Avoid relying on family members for such explanations.
- In your assessment, check that the patient’s health needs have been fully assessed, and that they and their family/carers have understood the diagnosis and any information they have been given.
- Don’t assume that the older person and their family/carers understand different terms and services (e.g. ‘home care’, ‘social workers’ or ‘district nurse’). Explain what services/professionals do.
Dignity, ethnicity and care

In a review of best practice and guidance in the UK relating to elders from minority groups, the following issues were identified as key:

Care plans
Care plans need to address social, cultural and religious issues (Standard 3, DoH, 2001b; Standard 2, DoH, 2001a).

Service information
Information about services should be in language and formats that suit multicultural populations (Standard 2, DoH, 2001a; Standard 1, DoH, 2001b).

Religious, cultural and dietary preferences
Consideration of the religious, cultural and dietary needs of service users, including maintaining privacy and respect at all times (Standards 10 and 15, DoH, 2001b; DoH 2001c)

Activities and interests
Individuals should be given choice in their use of leisure time and cultural interests, including maintaining contacts with local communities and local events (Standards 4, 12, 13, DoH, 2001b).

Death and dying
Religious and cultural views to be upheld in caring for those who are dying (Standard 11, DoH, 2001b), with a focus upon dignity (Standard 11, DoH, 2001b).
Ensuring the dignity of minority ethnic elders is not significantly different from ensuring the dignity of all patients. The care-planning process will remain the same, with specific attention being given to cultural, religious and social differences. Good care planning can also help to prevent social exclusion, which can lead to loneliness and isolation.

Minority ethnic elders, in common with all older people, are very different as individuals, and the approach to care will differ accordingly. In order to provide personalised care you will need to listen to patients and carers and support them to express their needs and preferences.

Essentially, to ensure that minority ethnic elders in hospital are treated with dignity, your aim should be to support your patients with the same respect you would want for yourself or a member of your family.

**Resources and references**

PRIAE Policy Research Institute on Ageing and Ethnicity
[www.priae.org](http://www.priae.org) See in particular health-related publications in Dementia (CNEOPSA); Palliative care (PALCOPE); Hospital care. Forthcoming publications including films in AIM Active Ageing; Patient Diary in Hospital Care/Long-term Conditions (SCEES)

Classification of ethnic groups
http://www.statistics.gov.uk/about/Classifications/ns_ethnic_classification.asp

Office for National Statistics (2004) Focus on Older People overview
http://www.statistics.gov.uk/focuson/olderpeople/default.asp


The Department of Health’s Audit Tool was developed to assist local councils in England in reviewing their services to minority ethnic older people. It is available online at www.doh.gov.uk (search on ‘audit tool’)

**References**


http://www.cancerbackup.org.uk/Healthprofessionals/Reachingmorecommunities/BeyondtheBarriers


4 Deepak, N. op.cit.

5 ibid.

http://www.med.umich.edu/multicultural/ccp/commun.htm#learn

7 Deepak, N. op.cit.

8 ibid.


