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## **Dignity Guide**

**Working with older people from minority ethnic groups – A guide  
for hospital staff**

**working with Help the Aged**

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## **Background**

This pocket guide has been developed by the Policy Research Institute on Ageing and Ethnicity (PRIAE). PRIAE (pronounced 'preeya') is an independent registered charity working to improve pensions, employment, health, social care and housing, and quality of life for black and minority ethnic elders in the UK and across Europe. The guide draws upon current research, policy and good practice particularly from PRIAE's health specific in work with elders from groups most commonly referred to in the UK as being 'minority ethnic'.

Note: The guide is not intended to guide the clinical treatment of patients.

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## 1. Introduction

“Old age means dignity. Having good friends, having peace of mind, also the ability to contribute to the community,” **Mr M A Khan Lodhi, speaking in the PRIAE film 2007 ‘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 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 neglect you, it is then not that far to reach the bottom,” **Mrs Shantaben, PRIAE Elder Volunteer speaking to PRIAE staff while in hospital 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**

This guide aims to provide information and ideas that will help you and your multi-disciplinary team in responding to the different needs of minority ethnic elders. Both the National Service Framework for Older People (2001) and the Race Relations (Amendment) Act (2000) aim to improve services for minority ethnic elders and to 'root' out discrimination. However, there is increasing evidence that ethnicity is a cause of social and health inequalities amongst 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

## 2. Minority ethnic elders and dignity

### What is it like for elders from minority ethnic elders 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.’

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 effect 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 dissatisfactions 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?

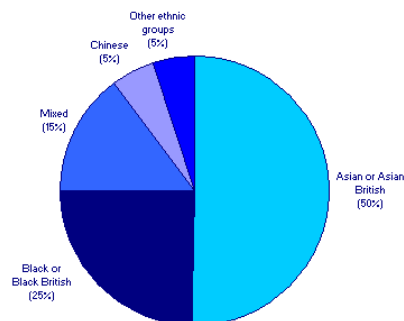
- 'Being treated like I was somebody.'
- 'A cheerful, friendly atmosphere'
- Good nursing care
- A clean environment
- 'Having some control over my stay'
- 'Doctors who take the time to explain things'
- Staff who came from a similar background
- Good post-operative care

From PRIAE (2001) Dignity on the Ward, for the Help the Aged Dignity on the Ward Campaign

### 3. Ethnicity, culture and old age

According to the 2001 census 7.6% 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, whilst Chinese people account for about 5%. 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, amongst 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 an 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 aged 50 and over were from minority ethnic groups
- minority ethnic elders often live with several different health conditions (co-morbidity), they can be poor, socially marginalised and have low expectations of services
- the most prevalent life-limiting diseases amongst minority ethnic elders are coronary heart disease and cardiovascular conditions, with other chronic conditions being diabetes, arthritis/rheumatism, lung/breathing problems, osteoporosis and kidney problems
- elders from Bangladeshi and Pakistani groups are more likely to have a limiting long term illness
- there are lower levels of awareness of mental health conditions such as depression and dementia amongst minority ethnic communities.
- many minority ethnic elders have low incomes, with approximately 40% in the UK receiving social benefits or allowances. Overall, those from minority ethnic groups have higher rates of unemployment, compared to their white, British counterparts.
- approximately 36% of South Asian elders and 82% of Chinese and Vietnamese elders do not speak English (UK MEC Study 2005)
- a significant problem for minority ethnic elders is the lack information about services and the availability of information in their own language
- the provision of places to worship and feeling able to talk freely about religious practices/needs are important aspects of health and social care provision for many minority ethnic elders

In order to provide personalised care to minority ethnic elders, it is important 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's uniqueness.

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.



#### 4. Providing culturally responsive care

‘An elderly Bosnian woman being admitted with terminal cancer may present the following challenges for health care staff and organizations: 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. As the above example from the Office of Minority Health shows, such care can involve the provision of practical services such as interpretation and advocacy. It can also involve more focussed 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 in exploring and thinking 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? E.g. cultural beliefs can include attitudes to pain, emotional expression and beliefs about the cause of an illness  
How might such beliefs affect care and treatment choices?

Example: For some Hindus, illness can be understood as a result of a person's '*karma*' – previous actions/thoughts. Such beliefs may lead to feelings of guilt or shame about an illness.

**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 and 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?  
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. Have you made any provisions in your institution/ward to enable patients to practice their religion? Do you have a list of faith-based organisations in your area?

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

Example: Illness and being vulnerable can be a time when patients 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. You do not have to memorise 'cultural facts' about different groups – look for the person not a stereotype!**

## 5. 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 cross-culturally)
- 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

### Principles in working with elders who not speak English

- Always try to use a professional interpreter for the initial assessment. During this assessment find out about the patient's preferences for future communication.
- Ensure that the patient understands that the interpreter is a professional and that information will be kept confidential
- When using professional interpreters, meet with the interpreter beforehand and explain the patient's situation. Tell the interpreter if 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 is 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

\*Berlin EA. & Fowkes WC, Jr.: A teaching framework for cross-cultural health care: application in family practice in Cross-cultural Medicine. Western Journal of Medicine. 1983, 12: 139, 934~998

'I think having that time to do a very in-depth assessment is vital because that will then 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? How do you think it works?
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?

## 6. 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, because 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 and 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 such as pain and symptom control
- *Inflexibility* - patient needs can 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 has all the information they need and in an appropriate format
- If printed material of essential information in the right language is not available, or the patient cannot read it, consider using other media such as audio-recording in the patient's own language
- 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.

## **7. Dignity, ethnicity and care**

In a review\* of best practice and guidance in the UK relating to elders from minority groups, research has identified the following issues as being important:

### **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)

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\* Freda Mold, Joanne M Fitzpatrick, Julia D Roberts (2005)

Caring for minority ethnic older people in nursing care homes, *British Journal of Nursing*, 2005, Vol 14, No 11, 601-6.

DoH (2001a) *National Service Framework for Older People*. DoH, London

DoH (2001b) *Care Homes for Older People: National Minimum Standards*. DoH, London

DoH (2001c) *Caring for Older People: A Nursing Priority. Integrating Knowledge, Practice and Values. Report by the Nursing and Midwifery Advisory Committee*. DoH, London

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Remember that ensuring the dignity of minority ethnic elders is not significantly different to 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 and to the effects of social exclusion that can result in loneliness and isolation.

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

One of the most significant recommendations of the Dignity Challenge that will help guide your work with minority ethnic elders is that you should try to ‘Support people with the same respect you would want for yourself or a member of your family.’

## **Resources**

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](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>

Official Documents – Health of Ethnic Minority Groups 1999 Report



**<http://www.archive.official-documents.co.uk/document/doh/survey99/hses-00.htm>**

Guidance and information about the Race Relations (Amendment) Act (2000) is available from the Commission for Racial Equality [www.cre.org.uk](http://www.cre.org.uk)

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/scrg/race](http://www.doh.gov.uk/scrg/race)