



Pakistani End of Life Care Strategy Consultation (EoLC)

In conjunction with NHS Newham and the Newham LINK,
paving the road to equality in health and social care.

This report is a response by Newham LINK following a consultation with the Pakistani community on the End of Life Care Strategy in Newham. We arranged this event in partnership with Fair and Share, a women's group working from the Katherine Road Community Centre in Forest Gate, on the 26th March 2010.

44 people were in attendance and participants were asked to respond to four key questions on the day, following a presentation.

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The four key questions:

- 1] How would you, a member of your family or a friend of yours, like to be cared for at the end of their life?
- 2] What do you think stops this from happening?
- 3] Are there any specific cultural and religious aspects that need to be considered when planning End of Life Care support services?
- 4] Are there any additional support needs?



44 women were in attendance and they participated in small workshops facilitated by the Newham LINKs Team. Following a slide presentation, participants were asked to respond to the above four key questions.

Identifying the target group:

Fair and Share were contacted, who meet regularly at the Katherine Road Community Centre in Forest Gate. The group's members are predominately Pakistani women. When planning this event, we met with the Co-ordinator and with members of the management committee of Fair and Share. They were really interested in the End of Life consultation and it was agreed that a consultation would be held at the end of March. The management committee asked for it to be held on a Friday evening, so that the women could participate without worrying about family commitments. They also said they would like it in a different place than the Katherine Road Community Centre as they were always meeting there. After much searching, the agreed locality was the Touch of Green restaurant which was newly opened in Green Street.. The event

offered a three course meal and entertainment provided by an Asian woman poet for the evening. This created a lot of interest and within a week of publicising the event, we had the numbers required plus a waiting list.

To maximize the level of participation, it was agreed that all relevant information would be translated into Urdu. This included any publicity and the main slides from the presentation. An Urdu interpreter was also booked for the event.

Format of the day:

As Fair and Share members had previous experience of being involved with Newham LINK consultations and due to space restrictions at the Touch of Green restaurant, we did not use the same format that we used for the Chinese consultation held two days earlier. We also reduced the content of the End of Life strategy presentation, as we realised it was too long.



We started the event with a presentation from the End of Life Care Service Improvement Lead from NHS Newham and the Director of the Forum for Health and Wellbeing.

Participants were asked the four key questions outlined in the previous page and broke up into working groups with facilitators, who could communicate in their community languages.

Following the consultation there was a poetry reading from a local female Asian poet, who had also participated in the consultation. Participants were really moved by her especially when she decided to read out a poem about her mother who had recently passed away.

What the local Pakistani community said about EoLC:

Hospices and Hospitals

Participants expressed concern that only 6% of the Newham community were using St Joseph's hospice. They felt that

the service providers were not informing their community of this service and as a result they were missing out. They wanted the NHS to arrange a visit to the hospice for Fair and Share members. Participants were informed that this could be easily arranged for them by NHS Newham.

Family rooms needed to be provided in the hospice for relatives to stay over.

Some said hospices were not good as you don't live long once you are there.

Some suggested an Asian hospice was needed in the area.

The women said that hospitals and hospices should have gender based wards. They also talked about gender specific nursing staff being available to care for them or their family members.

Taking parents to a hospice would be seen as dumping them by the community and they were worried about what people would say.



GP's:

Many said that 'GPs don't tell us about hospices. Asian doctors tell us to be grateful for the services we are getting as we would not get them back home'. Other complained that 'Asian doctors speak to us in English when they know we cannot understand them'. Participants felt that GPs who are patient centred, were more likely to provide them with a better service. However, they felt that with all the doctors' current work pressures they are far too stressed to treat them sensitively or offer them choices and alternatives.

Staff:

People said:

Staff needed to be friendly and respectful. They want culturally aware and trained staff, so that they were not racist towards them. They want more Asian NHS staff members to be available to care for them. They want regular and consistent visits from District nurses.

Religious /Cultural needs:

Islam emphasises responsibility to care for elders. However, some people felt they would honour that but would not expect their children to take the same

responsibility.

Religious and cultural needs need to be met in hospitals and hospices, as if they were at home. This was one of the reasons why dying at home was the preferred option. They want a prayer room within hospitals and hospices.

Family/ Carers:

People said:

They did not want to be a burden on their families. They wanted support for carers. They wanted professionals to listen to the carers as well as the patient. Participants felt that professionals did not listen to families. They talked about self respect and their roles as carers.

People said they want to die around their families and not alone. They want to be looked after properly and felt that home was the best place for that. There was a clear divide in the room between those who expected their children to care for them at the end of their lives and those who did not. However, many had not spoken of their expectations to their children. There were others who did not want to be a burden to others.

People mentioned that in England people are told if they



are dying. Back home this information is withheld by doctors and families. Most participants felt it was good to know the truth, so that they could prepare themselves.

Organ donation:

There was a debate about organ donation and mostly people felt that they needed their organs for the after life. The younger generation however, felt that this needed to be debated more thoroughly as they were happy to accept other peoples organs to save their lives. They would welcome input from religious scholars in this debate.

Information:

Only 9 out of the 44 women had received a guide to health services that was distributed to all households in the borough in English. NHS Newham offered to translate this on request.

People needed to be informed about services in their own language.

General Comments:

Participants wanted to maintain their dignity whilst dying.

Death and end of life care was not a subject that was discussed much within the community. People suggested the use of Asian Media to get messages across around End of Life Care.

The group valued the opportunity to discuss this subject, Many were not convinced that End of Life Care from the NHS would be 24/7 and that they would still need family support to have 24/7 care in the home. One woman said she lived at home alone but still wanted to die at home, but she was concerned that the NHS would not support her to do so as her children were not there.

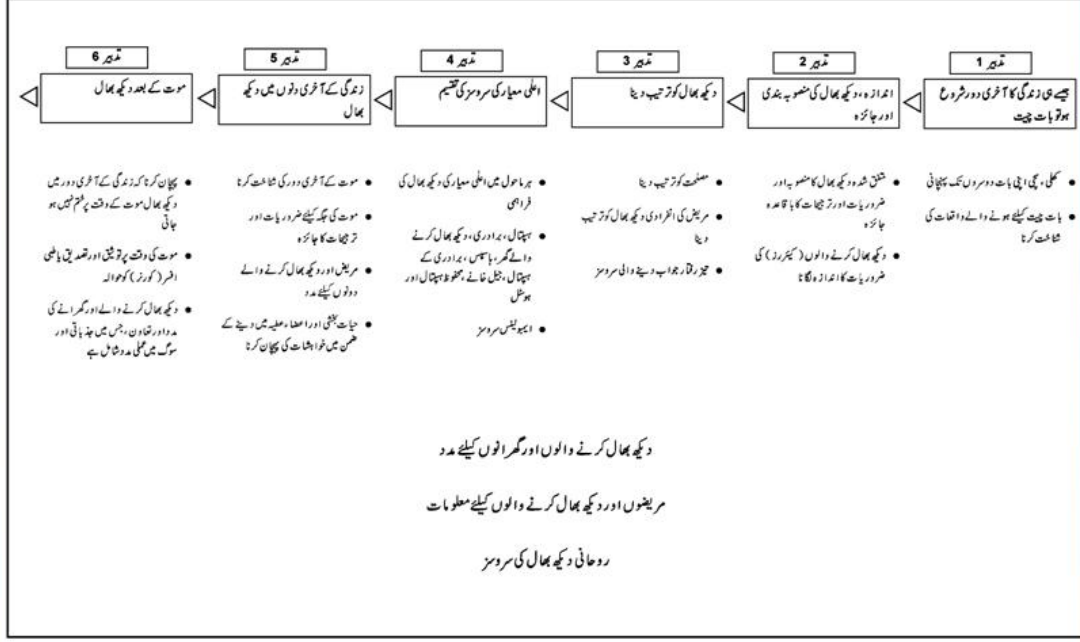
Some people preferred to die at home, but there needed to be the care and equipment available to enable this to happen.

People agreed, that looking after a dying person is very hard and not a task to be taken lightly. It is very hard for older carers as some of the tasks are very exhausting and need more than one person to carry them out, for example, changing wet or soiled sheets.

Appropriate home help should be available and it should be consistent, reliable and given at the time specified.

زندگی کے آخری دور میں دیکھ بھال کا راستہ

(The End of Life Care Pathway)



بات چیت سوالات (Discussion Questions)

آپ کیا چاہیں گے کہ آپ یا آپ کے گھرانے کے کسی فرد دوست و احباب کی زندگی کے آخری دور میں ان کی دیکھ بھال کیسے کی جائے؟

آپ کے خیال میں وہ کون سی چیز یا چیزیں ہیں جو ایسا ہونے سے روکتی ہے؟

کیا ایسے کوئی خصوصی تہذیبی یا مذہبی پہلو ہیں جن پر زندگی کے آخری دور میں دیکھ بھال کی مدد کی سروسز کی منصوبہ بندی کرتے وقت غور کرنے کی ضرورت ہے؟

زائد مدد کی ضروریات؟