No Secrets

Helping families and carers talk to children about life-limiting illness

GUIDE FOR HEALTHCARE WORKERS IN MALAWI DR MARY BUNN

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This booklet is based on research evidence from around the world and from Malawi on talking to children with life-limiting diseases, together with experience of working in a children's palliative care service in Malawi. It aims to help healthcare workers talk to children about their illness.

TELLING CHILDREN ABOUT LIFE-THREATENING ILLNESS: THE RESEARCH

In 2008, a group of researchers looked at attitudes towards talking to children about life-limiting disease and dying in different countries across the world. Researchers then investigated the same issues in Malawi, looking at Umodzi, a children's palliative care service based in the paediatrics department of Queen Elizabeth Central Hospital, Blantyre.

Across different cultures and countries, the researchers found that children knew more about their illness than they had been told, wanted to be told more and did better if they had had open and honest conversations about their illness.

In Malawi and in many other countries, the researchers found that:

- The children knew much more about their illness than they had been told.
- The children knew when they were not going to get better and when they were dying[1] without being told.
- Children with cancer wanted to be told about bad news, when the treatment was not working, and if they were likely to die soon[2].
- The children showed less anxiety and depression if they were told openly and honestly about their illness from the start[3]. They said that being able to talk about death and be reassured it could be peaceful and free from pain was important[4].

- The children felt very isolated if they were not given permission to talk openly. They wanted to express their fears and their love – and say goodbye[5].

However, in Malawi, families/carers told researchers that they were reluctant to tell children because:

- They believe that the child will lose hope, give up and die more quickly.
- The child might even commit suicide.
- They are too sad themselves to tell the child.
- It is impossible for families/carers to accept that a child will die and they do not want to give up hoping for a cure.
- They love their child too much to make them sad or disappointed.

The findings from the research supported what we know from our work at Umodzi.

We often felt children suffered additionally from the distress of uncertainty, false reassurance and not being allowed to talk or ask about worrying symptoms.

The older children and teenagers in particular recognised when they were not getting better.

Families/carers often reassured children that God would heal them. However, we felt that they would have benefited from understanding their medical condition and from knowing that modern science in Malawi was not able to cure them but could bring comfort and freedom from pain. It is widely recognised in palliative care that while we hope for the best, we also prepare for the worst.

STEP 1: PREPARING YOUR HEALTHCARE TEAM

- First, make sure others in your healthcare team agree that families/carers should be encouraged to tell their child. Many will share families/carers' concerns and will need to explore their own attitudes and understanding before being able to advise families/carers.
- Agree on a team approach and review it regularly. Staff may gradually change their attitudes after they have had more experience of talking with families/carers and children.
- Make sure that you and your staff are able to refer children and families for spiritual care that addresses the questions both children and adults may have about the impact and implications of the illness.

STEP 2: TALKING TO THE FAMILIES/CARERS

At Umodzi we found that holding discussions with groups of families/carers works well. You may be able to do this by getting families/carers of children with serious, chronic or life-limiting illness together to share their thoughts, worries

Q: WHO SHOULD TELL? MEDICAL STAFF OR FAMILIES/CARERS?

Children sometimes say they would like to be told by a doctor because they think that the doctor will give them more accurate information. But most families/carers feel strongly that they should be the ones to tell their children about their illness and they should decide how much to tell them.

Despite this, families/carers can find it very difficult, and need health workers to advise them and work together with them. By working together with families/carers, health workers can also make sure that children get accurate information.

If families/carers want the child to be told but cannot bring themselves to do it, you can offer to do it on their behalf, preferably in their presence. If they do not want the child to be told anything at all, continue to offer them the best support you can.

The children I see who know their status participate in their treatment and they are living well. They take their drugs properly because they were told.

and experiences, and then discuss together what they feel it would help their child to know. Whatever approach you decide to take:

- Explain the benefits of talking to children about their illness. Reassure them that rather than increasing anxiety, it may actually make the child less frightened.
- Give families/carers time to think about the problem and discuss what to do with the rest of their family.
- Remember that families/carers will not find the process easy. You could try exploring different role play scenarios addressing their concerns. For example, act out how they might respond if a child reacts very strongly when they receive the news.
- Consider providing information materials in families/carers' own languages.
- Make sure families/carers are aware that you will give them support to care for the child and give them the highest possible quality and meaning to their life until the end.
- Explain that the child's pain will be managed and that they have the option to go home and spend time with the wider family.

Q: HOW DO I APPROACH THE SITUATION IF MY STAFF/COLLEAGUES ARE RELUCTANT TO ENCOURAGE FAMILIES/CARERS TO TELL THEIR CHILD?

Try to find out whether this is because your colleagues find the subject difficult to discuss, or because they feel that talking to children about their illness is harmful.

If it is difficulty and fear of saying the wrong thing, help them to realise that families/carers feel this way too and practise different role play scenarios to give them confidence. If they feel that telling children is the wrong thing to do, keep discussing and learning together, and give them time.

Knowing helps to allay children's fears, that it might be that it is witchcraft for instance, so explaining helps a lot.

STEP 3: TALKING TO THE CHILD

- Explain to families/carers that it isn't necessary to tell a child everything all at once. You can share the information over a period of time, depending on the child's age and development. But do make sure that you tell the child before they find out by accident.
- Encourage families/carers to plan in advance how they will tell their child as this will make it easier for both them and the child.
- Encourage families to talk together in comfort and in private, not in a crowded hospital room.
- Emphasise the importance of being loving and reassuring.
- Explain that it is best to be responsive to the child's mood. Answer the questions the child asks, giving the amount of information they and you, the health worker, have decided is appropriate at that time.
- Families/carers should make sure the child knows that having a serious illness does not mean they will die straightaway. Explain that it is essential that children know that their life is still precious and that they will continue to receive medicines for pain.

Q: SOMETIMES CHILDREN ARE VERY ILL AND THERE MAY NOT BE ENOUGH TIME TO DELIVER INFORMATION IN STAGES. WHAT DO I DO THEN?

It is important to find out what both families/carers and the child already know, how they are coping and how the adults are talking to the child.

Again, informing the families/carers of the benefits to the child of understanding more about their illness, and the importance of open communication may be all you can do. Then leave it for them to think about and discuss with the child at home. Encourage them to come back again for further explanation if possible. It might be appropriate to give them a copy of this booklet.

Q: SHOULD ALL CHILDREN BE TOLD?

There may be a small number of children who will not benefit from talking about the seriousness of their illness. For example, very young children, those with developmental delay or severe emotional disturbance. In some cases it may be necessary to wait until they are older. Or it may be necessary not to talk at all, but just to continue to provide love, care and support.

STEP 4: WHAT HAPPENS NEXT?

- Children will obviously react in different ways. All children will need reassurance, love and support in exploring and coming to terms with their feelings, fears and anxieties. Most will accept the diagnosis over time, and be relieved to be given an explanation and freedom to talk about it. However, there may be some who go into a state of denial, or become depressed or have suicidal thoughts.

- Be aware of the signs to look for and know how to respond.

- Refer to a doctor with a letter of explanation about the illness and the child and family's understanding of it, if you feel that anti-depressant medication or more specialised help is needed.

- You may find the following organisations can offer you further help and support:

  Umodzi Clinic
  Queen Elizabeth Central Hospital
  Post Bag 360
  Chichiri
  Blantyre
  Malawi
  Email: Umodzi Team Leader, Fred Chiputula, at
  fchiputula@medcol.mw.

  Palliative Care Association of Malawi (PACAM)
  PO BOX 32625
  Mangochi District
  Malawi
  Email: pacam@sdnp.org.mw

  International Children's Palliative Care Network (ICPCN)
  PO Box 38785
  Pinelands 7430
  Cape Town
  South Africa
  Website: www.icpcn.org.uk

ANDREW'S STORY

15-year-old Andrew had been ill with coughing and chest pain for as long as he could remember. He found out that the cause of his symptoms was HIV/AIDS by accident when his health passport was left on the table. He was upset at first, but mainly because he felt people were hiding things from him. He felt that he had a right to know as he was the one suffering. Andrew says that he wished the doctor had told him as he had a lot of questions about his illness and thought that the doctor would not hide the truth. He felt he couldn't discuss his illness with his mother because he knew his mother was worried and didn't want to upset her even more. However, once he knew what was causing him to feel ill, he was able to stop worrying about his illness. Sadly Andrew continued to get worse and he died without ever being able to talk to his mother about his condition.

JOYCE'S STORY

14-year-old Joyce has HIV/AIDS. On a visit to the hospital, she was sent out to play so that the doctor could talk to her mother. Her mother then told her about her serious illness in the peace and quiet of their own home. 'My mother said that I did not have to be worried,' says Joyce. 'I said yes and I accepted it.' When Joyce and her mother next went to the hospital, the doctor asked her about her illness and she was able to tell him how she was. 'He said that it was much better that I knew why I was taking the medicines,' she says. 'I know my mother loves me and is telling me so I can protect myself.'

Please note that where we refer to 'families/carers' in this leaflet, this includes all those who are caring for a child, whether parents, guardians, relatives or other carers.

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REFERENCES AND FURTHER READING

If you would like to find out more about this international research, these resources may be helpful:

1. Bluebond-Langner M. The private worlds of dying children. Princeton University Press, 1978.

2. Dunsmore J, Quine S. Information, support, and decision-making needs and preferences of adolescents with cancer: implications for health professionals. Journal of Psychosocial Oncology 1995; 13(4): 39-56.

3. Last BL, van Veldhuizen A. Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8-16 years. European Journal of Cancer 1996; 32(2): 290-94.

4. Jankovic M, Spinetta J et al. Communicating with the dying child: an invitation to listening. A report of the SIOP Working Committee on psychosocial issues in pediatric oncology. Pediatric Blood Cancer 2008; 50: 1087-88.

5. Beale E, Baile W, Aaron J. Silence is not golden: communicating with children dying from cancer. Journal of Clinical Oncology 2005; 23(15).

And also

- Kreicbergs RN, et al. Talking about death with children who have severe malignant disease. New England Journal of Medicine; 351 (12): 1175-86.

For more information about Dr. Bunn's research at Umodzi, please email marybunn@blueyonder.co.uk

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