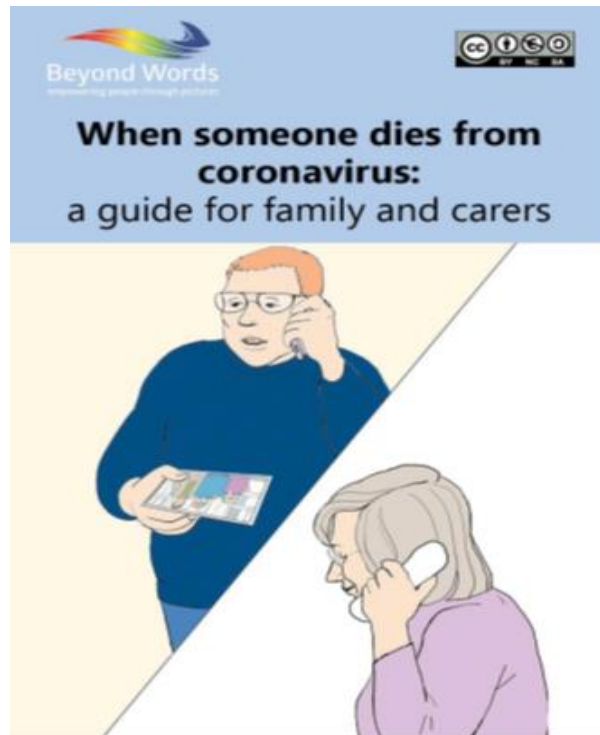


Don't Forget Me

Using symbols, pictures and music to pray when people are sick or die.



C Gangemi © 2020

Made with kind permission of Books Beyond Words and Widgit
Promoting and applying creative communication.



*Remembering and supporting
people who die and their loved ones*

Cristina Gangemi MA

THE KAIROS FORUM

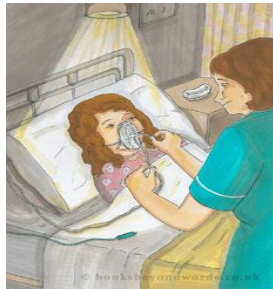
14 APRIL 2020

Introduction

Talking about and facing death is never easy. In this time of Covid pandemic, it is something that we must think about and be ready to do. This is important if you live with a person who has an intellectual disability or if you live in a family setting. When a person communicates creatively, activities need to be visual and meaning-full. Books Beyond Words are experts in using creative methods of communication and for sharing about death. BBW have created a brilliant resource with guidelines that can help when a person is sick or dies. Kairos also has had a lot of practical experience accompanying people to death and we have made some symbol cards and music to support the stories. You can print and cut out symbols or you can share them electronically by copying and pasting them on a phone message, on a Facebook page. This will help when we all practise social distancing.

Here is a summary of the Books Beyond Words guidelines. We do suggest, however, that you also spend time looking at the books, using the method and pictures to share and build stories. Our activities aim to help with prayer and spirituality. I have also made you some symbol strips, which can help you personalise the story if that helps you.

You can turn to the section / life situation that is most useful for you



The following guidelines are based upon ©BBW guidance 2020, written by Sheila Hollins and Irene Tuffrey Wijne. Resources can be downloaded FREE at <https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus>

Sharing about Death

- + Talk about death openly, honestly and simply. Answer all questions, if you know that a person will die, share that news, tell people about it, so it doesn't come as a surprise: you can say '..... is so ill, she/he is going to die'. You can use the '**.....might Die**' symbol card. (fig. 1)
- + Acknowledge how 'awful and difficult it is that we can't be with the person we love (after death) or be close to the body so as to say goodbye.'
- + Images of people being cared for can soothe anxiety.
- + If there is unfamiliar equipment (such as breathing equipment or masks), explain what they are used for, explain how they help.
- + Stefania Prandelli, the artist from The Kairos Forum, has made an image of a nurse in full protective scrubs, uniforms. If you need to, you can explain why nurses and staff have to be so covered. If there is a member of staff or a nurse present, in the suit, they can make themselves known by showing the picture and can even stick a matching image on their PPE (Personal, Protective, Equipment). (fig. 2)
- + Use the stories in the '**Beat the virus**' books or '**When someone dies**' book, or the **symbol sheets below** if you don't have time. As Sheila and Irene tell us, it is important to share honestly about death.
- + If you feel sad, it is OK to show that and to spend time comforting and being comforted. By sharing in this emotion and experience, you are present to one another showing empathy. This is the same if you are living with a person, if you are cared for by staff or if you are having to practise social distancing.

When someone is dying

- + Always maintaining social distance. Using a picture of the person who is dying, give a copy to each person, whether in family or residential setting when socially isolated. Create a time and method for praying for the person. This can help everyone feel involved and feel that they are doing something practical.
- + If people are socially isolated, they can make cards, prayers, paintings for the person who is dying. Where social distancing allows, these can be 'held up to a window, or given by staff/nurse to the person'.
- + Play the music Breathe, and I am here . You can find these on the website. If the person is or is not religious, you can follow the instructions card **Using music and symbols**. Use them according to religious beliefs. They can help you prepare for a person's death and accompany from a distance.
- + If the sick person is taken into hospital, after they have gone, sit together friends and family, where this is possible. Remember the person who is ill, share the '**..might Die**' symbol cards. Explain by following the symbol process: (see fig.2) **1**: Becoming ill, **2**: Being looked after, **3**: Being too ill to continue living, **4**: Dying and not being in the world.

When a person dies

- + During the Covid pandemic you will not be allowed to go near a person's body. Ask the nurse to take a photo of the person who has died. If a person wants, let them see the photo of the dead person and 'offer this opportunity' to everyone.
- + When the person dies at home, when the body is taken out of the house, mark this as an important event. Encourage people 'to stand by their own door or window to wave, clap, shout or stand in silence. What is important is that people have a chance to say **Good bye**'.
- + If a person dies in hospital, 'help the person to be in virtual contact with others who are affected by the death, especially their family – both during the illness and after the death'. You can use a phone or an Ipad (Ask about it in advance if you can).
- + Reassure the person and the rest of the family. Try to give the person dying a photo of the family and loved ones, this can also be shared with them virtually. As the person is dying, you can also encourage the use of the song ' **I am here** ' , or '**Breathe**' to be played on the phone so that, if the person is able to listen, they will know they are not alone. If the person is well enough, you can use the '**Why I am alone card**' (fig. 3), which can be shared on a tablet/smart phone, etc.. This will help them ask questions or express themselves.
- + Ask if the person wants to hear a blessing from their minister, or if they need a religious leader. If they are religious, you can reassure them that 'God will accompany them at all time, to keep sharing with God from their heart'.

***There are some prayer cards on our website that can help, we can amend them for all religious communities: cgangemi.kairos@gmail.com
<http://www.kairosforum.org/prayer-reflection/praying-when-people-die/>***

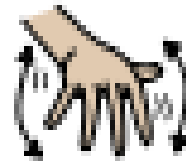
Remembering the person who has died

- + After a person dies, encourage some story sharing about the person who has died. Explain why the nurse was the only person to be able to visit. Explain why the nurse was in the suit (PPE) and why they are the only person allowed to go near their body.
- + Encourage people to use the '**Remember Me Card**' (fig. 4) to sing, to create a prayer corner so as to express how much the person will be missed.
- + Later, in the weeks that follow, share memories of life, joys and the days at the end of the person's life.
- + Never say the person 'has gone away', as it sets up false hopes of a person possibly 'coming back'. Explaining the finality of death will help you to explain the possibility of eternal peace with God. You can do this by using our symbol cards.

Fig. 1 might Die



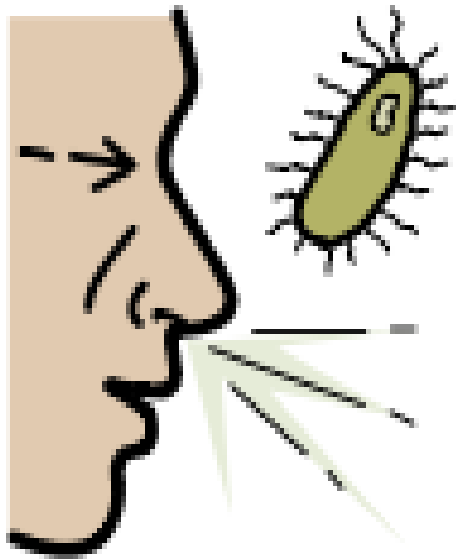
name



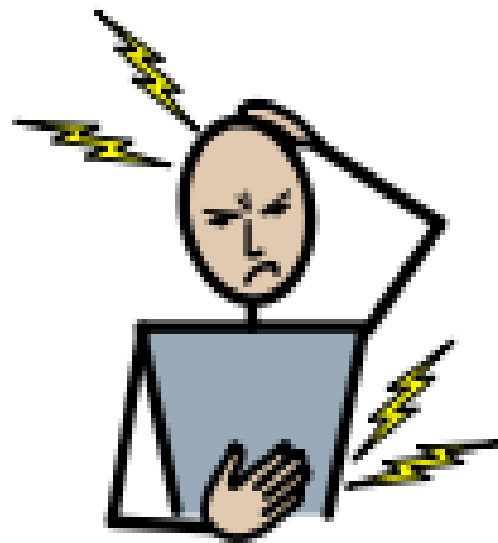
might



Die



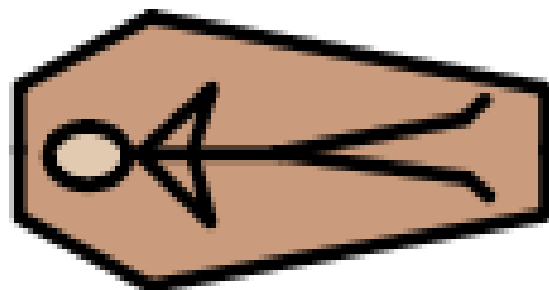
Covid virus



feeling ill



nursed



Dead

Fig.2 . Nurse or care worker in PPE

Take a photo of the person in PPE. Place the photo in the picture frame, or onto the suit itself. This can be done virtually or practically. Once printed, share with the person dying or with friends, families who are in anxiety. Please adhere to all hygiene issues surrounding the sharing of data or objects.

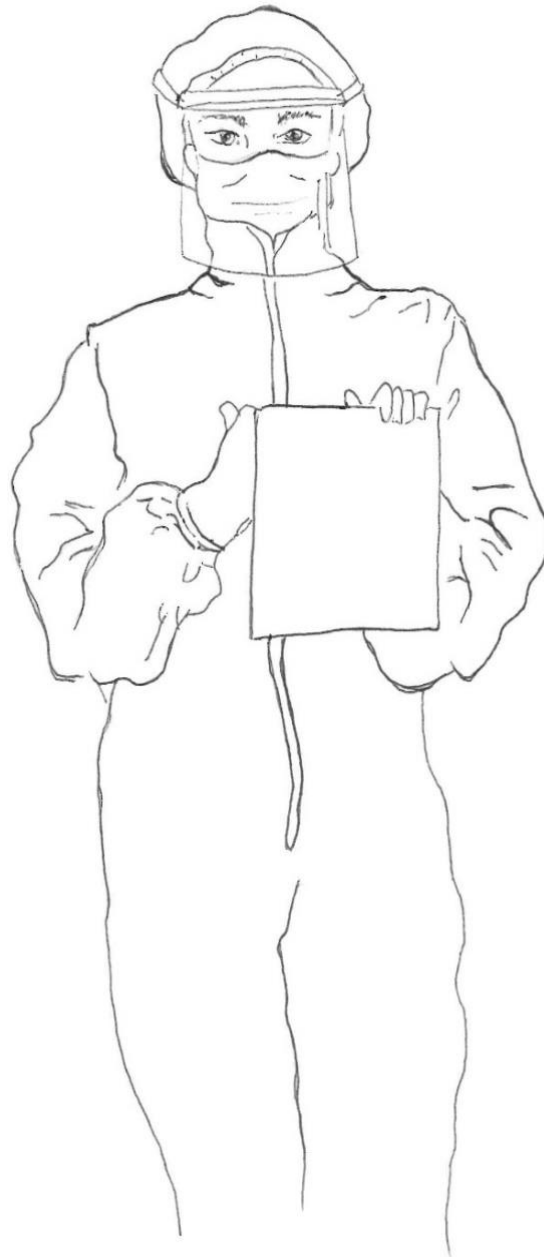




Fig.3. Why am I alone?




I am sick






only the nurse can help




 Name or Photo




 You have to be alone

 temperature cough headache





 oxygen mask help calm







 people are praying for you

Fig.4. Remember me



 name and Photo of friends

 Name and Photo of person who has died

Place a photo of friends , cut out and give to sick person to take to hospital, or keep near them. Or you can Cut and Paste

Place a photo of the person who has died. Cut out and give to family/friends to keep them near Or you can Cut and Paste

Using music, symbols and prayer (spirituality)

1. Copy, paste and send the symbol strip to the person who is ill, via phone. It can be sent as a photo on WhatsApp. Encourage the person to look at the phone if they can. **(fig.5. Music in Hospital)**
2. Play the music so that the person who is ill can hear. This can also be shared with people in a residential setting and socially isolated. It can be played in a room if the person is dying or has gone into hospital alone. Place this instruction on a hospital passport.
3. Sharing in the music will provide comfort for the person who is ill as well as the person who is concerned or bereft.
4. The **music "Breathe"** has been designed as a piece of music for creative and sensory learning, it is written to help the spirit be anima-ted. **The message is: "When you breathe, you can breathe with God. If you die, God breathes you in and takes you with His spirit". Breathe ©McKenzie 2020**
5. The music is played. This composition has been written to work in with a person's pattern of breathing. It is designed to move within a regular pattern of breath. This is especially important if the person experiences anxiety and is unable to deal well with sickness or nursing. The music can be used to help calm and address a breathing speed.
6. If the person dies, the music will accompany breathing and if the breathing stops, the music will accompany them into death.
7. The song **'I am here'** has been written as a song of accompaniment with carefully repeated words to help a person, who is sick or dying, not to feel alone. I am here **Message : The Spirit of God, The love of Christ is always near. Our Love is always strong and so you are never alone, we are near in spirit. ©Tobanelli 2020**
8. If the person goes to hospital, try and explain that the songs will be shared at home, that you will pray for them and that if it is hard to breathe, **they can allow the music help them, as God breathes with them in life and beyond (if religious).**
9. For friends and family who are not able to accompany the person who is ill, play the songs and reassure them that, by sharing in the music, they are supporting them. Take some time to pray, for the people who are at home or worried, give them the prayer cards to complete. **(Fig. 6, 7) Message: celebrating and remembering people we love, we know we love them because we miss them. Their life was important. We won't forget them.**

*Based on the writings and wisdom of phenomenologist
Edith Stein*

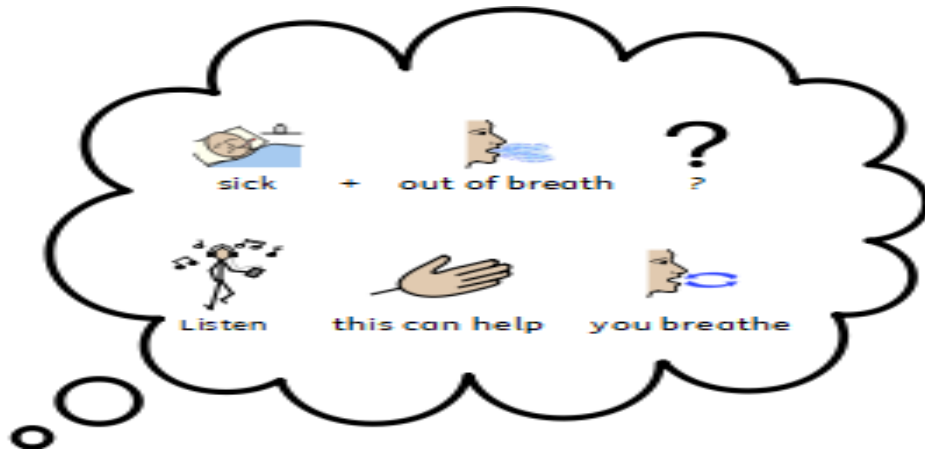


Fig.5. Prayer card

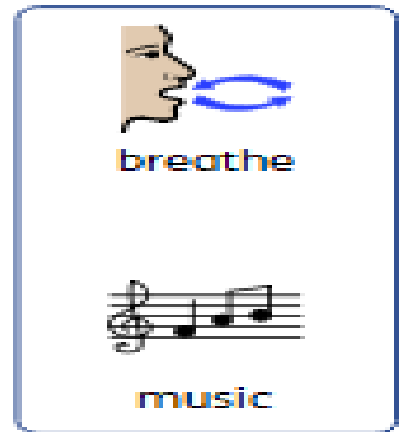
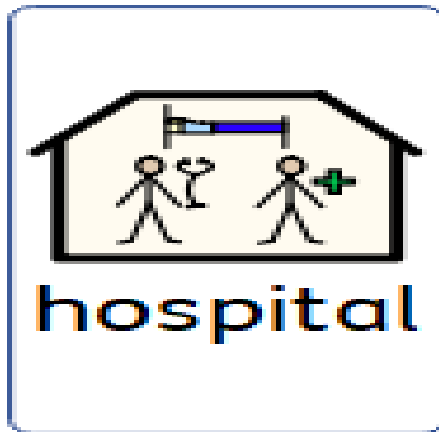
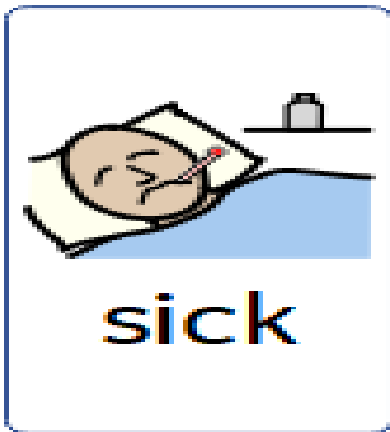


Fig.6. I pray for

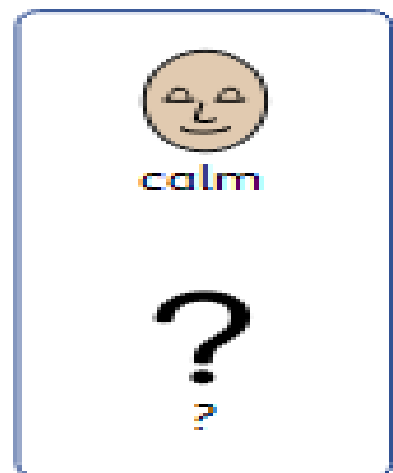


Fig.7. Prayer card



Here is a link to the music "Breathe": you can find it on the ['Praying through the Virus page'](http://www.kairosforum.org/prayer-reflection/praying-through-the-virus/): You can also share the prayer card below <http://www.kairosforum.org/prayer-reflection/praying-through-the-virus/>

We hope that this will help you prepare for people who may die and for the person who will mourn them. Please do use the Book Beyond Words Stories to enhance sharing and well being. Once social distancing is over, you could set up a book club, to talk through all that has happened. Attending to the importance of spirituality and sharing our stories are important for a whole person's approach to mental health. Religious beliefs are part of this.

Our work regarding the use of creative communication is based upon our research into the spiritual and religious needs of people with intellectual disabilities.

*You can find out more by looking at our website
www.kairosforum.org : EveryBody Has a Story.*

The guidelines have been developed in line with the guidance given by experts in the field, Baroness Sheila Holins and Irene Tuffre Wijne. Resources for sharing books and stories regarding the virus can be downloaded for free at :

<https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus>

You can find invaluable advice and access to resources on the web page of Irene Tuffrey-Wijne, who is a known expert and one of the first people to research into issues of Death and Intellectual Disabilities.

https://www.google.com/search?q=irene+tuffrey+wijne&rlz=1C1GCEA_enGB852GB852&oq=irene&aqs=chrome.2.69i59l3j46l3j69i60l2.3067j1j7&sourceid=chrome&ie=UTF-8

*Our prayers and thoughts are with you all
in these difficult times.*

*Cristina Gangemi and the Kairos Team.
14 April 2020*