

connecting to a loved one at a challenging time

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A Guide to Visiting the Dying connecting with loved ones in challenging times



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Why this guide is needed

Generally, anyone who is ill appreciates having visitors, and perhaps especially so when they are dying. To know that we are loved and valued in spite of no longer being able to fill most of the roles we once had is hugely reassuring. Conversely, when friends seem to have forgotten us or no longer call it can be hurtful and increase our sense of alienation.

In the past, people were cared for by their family and community. With death becoming increasingly medicalised and the dying assigned to institutions – primarily hospitals – most of us have little experience of what dying entails and how to be with a dying person. However much we may love our dying friend or relative, spending time with them in their last days can be confronting.

Potential concerns about visiting the dying

We might be apprehensive about visiting a dying person because we:

- Don't know what to say
- Fear causing upset or being seen as upset
- Think we need to have all the answers e.g. know how to reassure the person, understand what happens when someone is dying and even after death
- Imagine that others have more right to visit
- Are unsure as to whether our friend or their family wants us to visit
- Cannot visit at the times available or fear any involvement might impinge on our time
- Have some unfinished emotional business with the dying person that we don't want to address
- Are fearful of confronting our own death

You may find that some of the above are relevant for you. That's perfectly normal. In this guide we attempt to shine some light on these common concerns so that you feel more at ease with your visit. Whether you are visiting a family member, friend, colleague, patient or client, such an occasion can be a valuable experience for you both.

Especially if you are about to visit a sick or dying person for the first time, the amount of material might feel a lot to take in. Mindful of this we've tried to distil the information and suggestions as we think most helpful.

Our suggestion is: Read this guide through over a few sittings and trust that you'll remember whatever you need to. With subsequent readings you'll retain more points.



Planning your visit

There are various considerations to be aware of when you plan to visit a dying person.

How are you?

Be aware of how you are feeling and might feel once with the dying person.

Inevitably some emotions will be triggered. Entering a hospital with its busy, noisy atmosphere, the harsh lights and uniformed personnel, can be intimidating, as can be the hushed environment of a hospice and of patients in distress. In addition, as author and former palliative care specialist, Dr Barbato, notes, it is 'hard to be there for someone if we are weighed down by our own grief.' (1)

Seeing another facing their death can be a 'wake-up call' for us – a reminder that we too will die one day.

Distress

Visiting someone in a hospital or hospice can be distressing. Alternatively, when the normal, familiar feeling of being at the person's home is disrupted, it can be disconcerting to see the household routine now revolving around the dying friend and changes such as the living room being transformed into their bedroom. You might also feel taken aback by how drastically the illness has affected the appearance of the dying person or the evident degree of their pain.

It is normal to have such feelings. Just notice them and let them be. If you need to, afterwards you might want to share your feelings with a close friend or to shed tears. When sharing your feelings, it is good to be aware of the Ring Theory as described here.



A sense of helplessness

However much we love someone – and the more love there is, the more impotent we might feel – this is a situation that we cannot control, and that realisation can be unsettling.

Rather than fighting it, accept the helplessness. It has a value. It reminds us of the reality that we are fragile and that, when we do not resist it, helplessness has its own beauty and something to teach.

Expressing unhelpful emotions

Venting your grief or anger at life may not be of great help to the person you are visiting. If your feelings run counter to theirs – for example you feel that they should fight rather than surrender to what is – it may not be helpful to express them. Remember that your reactions might be more about you and your own attitude to what is happening rather than what is best for the other.

If your feelings are weighing heavily on you, find an empathetic listener to discuss them with or release them in the privacy of your own space.

What's happening emotionally to the dying person?

It's important to know where the dying person is emotionally. If there is a family member to whom you are close, another friend visiting the dying person, or someone arranging a visiting rota, check in with them (staff might be reluctant to tell you if you are not a family member). Otherwise, if appropriate, ask the person themselves and/or gauge what they are feeling through what is said (or not said) and non-verbal cues.

Not knowing what to say and do

You might be anxious about what to say and do; concerned about whether they know that they are dying and if you should encourage them to talk about that. And if they do, how you should respond. These concerns are addressed in the sections below.

Practical aspects of visiting

You'll want to know:

*Am I welcome? Ideally, a friend or family member of the dying person is overseeing their general care and you can check in with them to know if your visit would be welcome. (Much as they love their friends and relatives, the dying person might prefer that certain of them don't come by or they may not want to see anyone except their immediate family).

They may feel too ill, too tired, in pain, or be self-conscious about how they look. They may no longer feel engaged in the world, in other people and their lives, which seem increasingly irrelevant to their own reality. Sometimes, having a visitor can be like too much hard work. As Helen Fitzgerald writes: '[The dying person] may feel trapped in bed, being viewed by people they in fact would rather not see and having boring conversations.' (2)

* **Do they know that they are dying?** Find out from other friends or family if the dying person is aware that they are dying; what feelings they have expressed about it and whether they have been able to/want to talk about it. See <u>Telling someone</u> they are dying.

It is important that you know what's going on with them. This can change the way you relate. Dr Robert Buckman suggests three ways this might happen:

- 1.Understanding and recognising what the dying person is feeling and going through can reduce the fear and panic that you might feel, and help you function normally in abnormal circumstances.
- 2. Once you understand the emotions that the dying person is experiencing, you can respond differently than if you are oblivious of whether they know they are dying or not. For instance, you might be able to turn a potential argument into something that helps you both and brings you closer.
- 3. Having some guidelines to work with can help you stop feeling overwhelmed. By understanding the things that happen as someone becomes more ill and faces the threat of death you will be able to...plan resources. (3) See <u>Issues that may arise in dying.</u>

- * When is the best time to visit and how long should I stay? Whether they are in a hospital, hospice or their own home are there set hours? The dying person might feel at their best early on in the day or have more energy later on. Plan on short visits, which will be less taxing for your friend.
- * Do I need to see them immediately? It's not easy to assess how much longer a person may have, though it's reasonable to ask doctors whether there might be hours, days or weeks. Even so a terminal illness can often follow an unpredictable course and it sometimes catches people out. Unless you're specifically advised by the medical or nursing staff to come immediately, usually, though not always, there will be time.
- * Will others be there when I visit? Can I see them alone? Alongside your own desire to have a visit between just the two of you, be aware that there may well be other friends and relatives wanting that just as much. Each person has something to offer and no one can be all things to one person.

NB: if the dying person would like to see you, you have the right to visit.

- * Is the person likely to be in pain or drowsy? Aim to call the home, hospice or hospital before you set out to check that a visit would still be welcome.
- *Is there is anything I should bring or not bring? Your friend might enjoy reading or listening to music, for example, and would appreciate books or an ipad, rather than flowers or chocolates.
- * Is it okay to offer them a massage, some reflexology or a guided relaxationmeditation? See <u>Leading a guided meditation for the seriously ill or dying.</u>

If you're uncertain check with their doctor regarding the first two and of course with the person her/himself regarding any sessions such as these.



At the bedside

- * Immediately before entering the room, check with medical/nursing staff and/or a friend/relative of the dying person as to how the person is if they are comfortable and conscious; how they slept the previous night and how their emotional state is today.
- * If your friend or relative is sharing the room with others, to give you both and the other patients some *privacy* you could ask if they would like the curtains drawn around their bed.
- * Be sensitive about *where you sit.* A chair that is positioned in a way that suits the person might already be in place. Otherwise, ask where it would suit them to have you sit so that you avoid encroaching on their space. Sitting up close, on their bed for example, may convey your desire to be emotionally close but limit their ability to move easily or to protect themselves from pain. Sitting too far away might give the unintended message that emotionally you 'want to keep your distance.' Position yourself so that both of you can see each other's face easily.
- * The other's eyes may be closed. Sit down quietly and, if their eyes remain closed, this may be a good opportunity to close your own eyes and just relax. Sharing silence like this has its own intimacy. As well or instead: by consciously tuning into the other's breathing you can create a certain resonance with them. If you then watch your own breath, that meditative energy can be transferred to them. [More on silence below]

Even if they are in coma, you can still connect with them. Research indicates that people in coma can hear, so you can talk to the person, perhaps saying who you are, that you've come to visit for 15 minutes or so; that you'd like to just sit by their side for that time, or some such. See Communicating with a person in coma.

* If the other is alert, you'll want to *greet them*. Is your usual form of greeting appropriate? A short, gentle hug or hand holding might be more appreciated.

After exchanging greetings, check if there is *anything that needs doing practically*, such as offering them a drink or adjusting their blanket. Physical concerns are always paramount for someone confined to bed and can be a distraction.

* Throughout your visit be aware of their *body language*. For example, as you moved to kiss them in greeting, how was that received? Notice how they are sitting or lying, their facial expressions and movements: any of these can be indicative of pleasure or, conversely, of discomfort or of their being too tired to continue being engaged with you.



- * You do have a relationship with this person and you have known and loved each other for who you are and how you are. You are not expected to morph into a fount of wisdom or super-saint and to have any answers. In fact, your value can be in your simply being yourself; your connection can provide a much-needed 'touchstone of normality that dying people need from others.' (4)
- * Talk and generally be as you normally are with them, with the added awareness that this is a different context and adjusting accordingly. For example, your usual

boisterous manner might need to be lowered a notch or two (especially if there are other people in the room and even more so if you are discussing sensitive issues).

- * It may not always be appropriate now to regale them with the minutiae of your daily life. Be conscious that much as you may not like it, this *may be the last time* you see your friend. Make sure you say those things you want to such as reminiscing about shared times together and that you express your love and appreciation for them, and tell them what you have gained through knowing them. Then there is more of a chance that you won't have regrets when the person has gone. Allow time, too, to address any 'unfinished business' between the two of you. See Completing unfinished business.
- * The dying person might have a need to *talk about themselves* and have been hoping for a chance to do that with someone who is able and willing to listen. You may be that person, or would like to be but do not feel confident about how to respond. There are some basic pointers that can help you: see In-Rapport Skills.
- * Due to the effect of drugs or the disease process the dying person may not be able to collect their thoughts together as easily as they once did or may have trouble speaking. Sometimes sitting together in *silence* can provide all the intimacy and support that is needed. If your friend is tired, you can suggest that you both close your eyes and be in that space together.
- * As does silence, *touch* can also convey much that words cannot. A light hand on the other's, or a gentle caress, can be soothing and affirming of your affection.

As David Kuhl, M.D., writes: 'Through touch a healing process begins. Suffering is reduced; pain is altered. For [those with a terminal illness] perhaps even more so than at other times of life, touch plays an important role in reconnecting with others and in creating new connections.

'People who are dying often feel "out of touch" physically and emotionally. They feel that no one knows their experience. They feel isolated. They crave physical contact, not merely as a means of physical comfort or pain relief, but more significantly as a way to counteract the feeling of being untouchable and separate.' (5)

Concluding the visit

It is advisable to keep your visit short. Your friend or relative – weak, possibly in pain, and confined to bed – is a captive audience. Be sensitive to how they might be feeling and remember especially to look for non-verbal signals that might indicate that they are uncomfortable, tired or would prefer to be alone. Be aware, too, that there may well be other friends and relatives wanting to visit.

It may or may not be appropriate to set up another visit. The person may not want to prolong your visit by a discussion about this. And resist making promises that you are not sure you can keep. Maybe just an 'I'll be in touch!' is all that is needed, along with reminding them that you love them. Whenever you say goodbye to a dying person be aware that you two may not meet again.

Support from more frequent visitors

There are other aspects of being with someone who is very ill and/or dying. These can be of interest and support for you especially if you are visiting or intend to visit the dying person more often.

Additional resources on our website:

- * What it is to be a 'good listener' and other In-Rapport skills
- * Supporting someone through emotional changes
- * Being with someone who is in pain
- * Supporting someone in looking back on their life as a way to appreciate what it has meant to them; to revisit the joyful times, perhaps to find the lessons in the challenging times, and to notice wherever there are regrets and 'unfinished business.' See <u>Life Review</u>
- * Supporting the person in completing their <u>unfinished business</u> with others perhaps through letting them dictate a letter to you

Additional reading

How to say goodbye

What can I say to a friend who is dying?

The top 5 things to do when a loved one is dying

Preparing for your visit with someone in hospice care

How to offer comfort to someone who is dying

How not to say the wrong thing – The Ring Theory

A poem, 'A message from a dying friend,' by Jeff Foster

https://www.youtube.com/watch?v=cQC8VUp65Dk

Sources

- 1) Caring for the Living and the Dying Dr Michael Barbato (McGraw-Hill)
- 2) *The Mourning Handbook* Helen Fitzgerald (Simon and Schuster)
- 3) I Don't Know What to Say David Buckman (Papermac)
- 4) How to Have a Good Death Esther Rantzen (DK)
- 5) What Dying People Want David Kuhl, M.D. (Public Affairs)

Of these books listed *The Mourning Handbook* and *How to Have a Good Death* provide the most on this subject.



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Please visit our website <u>www.oshosammasati.org</u> for more on meditation support in living and dying.

Disclaimer

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