Some advice for relatives and friends

Dear Relative,

When a friend or relative receives the diagnosis that he or she has a life-threatening illness you will be affected too.

You will undoubtedly feel sadness and concern for that person but you may be surprised to find that, at times, you might also experience fear, anger, resentment, or even self-pity along with unexpected tiredness or listlessness. These are normal human emotions in response to unwelcome health news and you are not alone if you have these feelings and thoughts – we all do at times. We tell you this so that you won’t judge yourself as a bad or uncaring friend if unwelcome feelings do arise from time to time.

If, however, you continue to feel low or are concerned about how you feel you might decide to share your concerns with a friend or professional.

Medicine has moved a long way in the forty years I have been a doctor. Not everyone is cured of serious illness, including cancer, although many are. But the good news is that many, many people can now choose to have excellent relief of the physical or psychological problems which might have made the last months of life very unpleasant even ten or twenty years ago.

We none of us expect to live for ever – at least not in our current physical form. But I imagine that most of us would hope for a good death and we all have our own view of what that might be like. It should be possible nowadays for each of us to live the final days and weeks of our lives as we might hope – comfortable, physically and emotionally, and able to enjoy the family and friends we chose to have around us.

This is what palliative care is about. You can see the World Health Organisation’s definition at www.barbadospalliative.org/Definition.pdf

There are some links which you might like to explore (or to ask a friend to access with you if you don’t have a computer). Although it is written for a Canadian audience, we think that the www.virtualhospice.ca website is very helpful.

What can I do to help my friend or relative?

Firstly, we would suggest that you can listen. Allow your friend or relative to talk and make it your job is to listen hard and to remember. Try to allow your friend time to talk without interruptions. Obviously, this matters most in the days and weeks just after a diagnosis but it will continue throughout the course of the illness.

Respecting the privacy of your relative or friend

You need to assume that he or she will need the same privacy, or more, than you would have afforded before the illness. If in doubt about how much input is wanted or needed, ask.

It is important to allow the patient to be as independent as he or she can be
This must seem obvious but it is difficult for well-meaning friends to stand back and allow someone they love to struggle with a task that they could perhaps do in a moment. However, allowing your friend to be as independent as possible is one of your most important gifts to that person. It will apply if the patient decides to see the doctor alone, to take the bus to town, to cook and look after the house. And when they reach the point of needing more help, you can allow them their independence by putting them in charge of any decision choices they are capable of making. Help, please do, but make your friend the boss. And that sometimes means respecting decisions you disagree with!

**Being needed** is one of the things that protects humans from depression and mental illness. (That’s one of the reasons why elderly people are so attached to their animals) Being ill often robs us of that reassuring sense of being needed. It is very important to find ways to tackle this problem.

**Having fun together**
Remember good times, plan the days to come, perhaps sort through cuttings or family photographs to be left for the grandchildren, whatever seems appropriate to the circumstances.

**Keeping company**
It can be exhausting to be unwell. Sometimes a visit when your friend sits quietly with you or watches television with you is just what you want. It’s not about what you say to your friend, it’s about coming alongside to keep them company that means such a lot.

And most of all **listen to your instincts and then ask your friend if you’ve got it right.** Most of the time you will have!

**Looking after yourself**
It may seem unnecessary to say this but we say it nonetheless. All palliative care specialists recommend that carers take time for themselves. It stops burn-out for carers but it also improves the service to the patient! Plan to take little bursts of time off and, if possible, put them in your diary or kitchen calendar for the week.

Barbados Palliative Care is a very young service and we are just at the planning stage in our service provision so we cannot yet provide the service we might hope to have in place in the future. However, we will do everything we can to assist you or to direct you to a source of help if you have the need.