

Some advice for patients

Dear Patient,

The Barbados Palliative Care Association is here to help you in whatever way we can. Please contact us if you think we can be of assistance.

We have put some general thoughts together in the paragraphs below which we hope will be helpful. And there are also some links (www.barbadospalliative.org/Links.html) which you might like to explore (or to ask a friend 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.

Barbados Palliative Care is a very young organisation and we are still in process of developing services. We will do our best to help or to put you in touch with an organisation which can.

What is 'Palliative Care'?

The World Health Organisation's definition is at www.barbadospalliative.org/Definition.pdf

Your illness

Being told that you have a life-threatening illness instantly transports you to a very lonely place. It often takes quite a long time for the initial, very unreal feeling to go away. It is like coming to terms with a bereavement –and, indeed, losing health which you took for granted *is* a form of bereavement.

No-one will ever quite understand what it feels like to be in your shoes.

But, while this is so, you can also remember that many people wish you well – the doctors and nurses and health professionals who care for you all wish you well, and friends and family, also, wish you well. So, although it's lonely, you have very many people on your side.

And remember that being human is, by definition, a life-threatening condition so that all these professionals and friends and families will have had their own personal experiences of illness and death and are, in an actual way, sharing your journey.

We have included some thoughts, below, on having successful appointments with health professionals and on making the most of your health. Please feel free to feed back your thoughts on these matters.

Health Professionals

The health professionals who look after you hold important information about your diagnosis, treatment and prognosis. They want you to get the best possible advice on managing your illness but they may not understand where the gaps are in your knowledge. And with time restricted, they may even forget to ask if you have any questions. So *you* must be willing to ask *your* questions and to have them answered. This is where it helps if you have WRITTEN DOWN THE QUESTIONS BEFOREHAND so that your mind will not go a blank when the time comes. And, of course, you must make sure to ask for further explanation if you need to.

You might like to take a friend or relative along with you to a medical appointment – two pairs of ears are better than one. But if you prefer to go alone, do just that. And do remember the paper and pen!

Read information that's given to you as soon as you can so that you can change appointment dates, if necessary, and seek answers to any queries that might arise.

Eat well

Your need to give your body the best chance it can to function well. Different conditions require different adjustments to diet but, as a general rule and, unless your doctor tells you otherwise, eat small nourishing meals regularly. They should include, if possible, protein in the form of fish or meat or nuts or pulses (such as beans and lentils) or a mixture of these. It is also important to eat some fruit and vegetables each day. Have a glass of water or non-fizzy drink five times a day and keep your intake of coffee, tea and caffeine drinks low. That goes for the stronger things too!

You can access more information in the websites below.

Move

Regular movement is important; it stops the aches and pains that come from joints that are allowed to get stiff and it makes you feel good. If you already take regular exercise, try to keep it up, even if reduced for a while. It will help to keep you feeling 'normal'. And if you don't usually exercise you must start to do something every day – no matter how little to begin with. After a week it will make you feel better.

Sleep

Having a little exercise every day will help your sleeping. You will also sleep better if you don't doze too much during the day and if you try to avoid alcohol and very stimulating or distressing conversation or TV viewing just before you go to bed. Sleeping tablets are not a first resort and, obviously, will need discussion with your medical advisor if you think they might be necessary. .

Medicines

Your health professionals will keep you right so ask them. We don't propose to go into detail about specific medicines other than the few comments below. However, there is quite detailed information on some of the websites listed below and on the internet.

You must be aware that you must **never** take medicines that are prescribed for another person – they could be harmful to your condition or interact with medicines that you are already taking. And **you** have a responsibility never to give your prescribed medicines to another person. Medicines can often be used to treat a number of very different conditions. For example, a medicine that might have been prescribed and work miraculously for pain in multiple sclerosis might be prescribed to another patient for control of epilepsy. Now you can imagine how dangerous it might be if a well-meaning friend offered you her wonderful MS 'painkiller' to try for your headache. Please don't share medication!

And, finally, you should be aware that the painkillers from a group of medicines called 'opioids' can relieve pain very effectively but they pretty well always cause constipation. Your doctor can tell you if you are being prescribed one. If so, you will usually need to

take enough laxative *every day* to stay on top of the problem. It's important to talk to your doctor or nurse about this.

And, finally we suggest that you say 'yes, please' every time anyone gives you the offer of doing anything that's enjoyable or fun.