Providing care when cancer does not go away

Sometimes, cancer may not go away despite the best of treatments. This is usually the case when the cancer has spread to other parts of the body, away from where it originally started. Although long-term cure is unlikely, treatments can still be useful, focusing on controlling the cancer, so that your loved one has less symptoms from the cancer and/or extension of his or her life. Like all



big decisions, your loved one and you will still have to discuss with the treating team on the benefits and risks of treatment to better make a decision that suits his or her life preferences. Providing care at this point can be challenging, due to the sudden change in life circumstances, and the physical, practical, psychological and emotional problems your loved one and you may be facing. Although caring for your loved one appears to be the most important thing, it is also very important to look after yourself.

Understanding your loved one's preferences

It will be important for your loved one to make his or her care and treatment preferences known at this point. For instance, some people may want to have their lives prolonged as much as possible, while others may opt for comfort and quality of life. Some may want a combination of both. These preferences often change over the course of the cancer journey.

At some point in their cancer journey, further treatment may no longer be possible or preferred by your loved one. Although it is difficult, it is often useful to discuss the care your loved one prefers towards the end of his or her life. You may reach out to your healthcare team or refer to more information on end of life care and advanced care planning (http://www.singaporehospice.org.sg/advancecareplanning/), to help you with this discussion.

More treatment?

When cancer is not responding to the current treatment, one of the main decisions to make would be whether to try more treatment. The process of decision making may be accompanied by many emotions, such as sadness, anger and the question of how much longer your loved one will live. There is often no right or wrong answer to this. Some guiding questions you may use to reach a decision together with your loved one and healthcare team can include:

 What is the goal of this treatment? Is it to slow cancer growth or to relieve symptoms? Is it in line with what we want?

• What are the possible downsides of this treatment (e.g. side effects)? Do the

pros outweigh the cons?

During this time, it is even more vital to continue to have open communication with your loved one, as well as the healthcare team. Understanding what your loved one wants and having more factual information will make the decision making process easier.



Your emotions

It is understandably difficult when you receive news that your loved one would not be cured of his or her cancer. In addition, your loved one will likely need more care as his or her body becomes weaker, increasing the demands on your caregiving. Similar to what your loved one might feel, you may experience:

- Anger
- Sadness
- Helplessness
- Worry
- Fear

It is normal to feel any of the above, and it is important that you get as much as help as you can from your family members, friends or community networks, to support you during this stressful period. Speak to the medical social worker, share your feelings with close friends, find ways to manage your stress, and ask for help when you feel tired. Take care of yourself.

Supporting elderly parents



It is not unusual for people to be reluctant to share their cancer diagnosis and deteriorating condition with their elderly parents, for fear of upsetting them. As the caregiver, you may be feeling the same way. However, it is important to encourage an open environment where your loved one's parents' questions and doubts can be clarified. Although it is difficult for elderly parents to see the suffering of their child no matter what age they may be, they would still appreciate an opportunity to express their thoughts and feelings to your

loved one.

If you need to, tell them that what you will be sharing may be potentially difficult to hear, before breaking the news to them slowly and gently. Give them adequate time to absorb each piece of information, and be patient in clarifying any questions they may have. Do not hesitate to approach your loved one's healthcare team if you need any help in doing this.

Supporting children

Similarly, many people with cancer do not talk about their illnesses with their children. Being the caregiver, you may be in the position to speak to the children regarding your loved one's condition. Children should be given truthful information when they need it, in order to cope well from day to day.

Practical matters

Your loved one may also need your assistance in dealing with some of the practical matters listed below. You may want to visit the web links to find out more.

- Appointing Lasting Power of Attorney http://www.msf.gov.sg/opg/Pages.Home,aspx
- Making an Advance Medical Directive (AMD)
 http://www.moh.gov.sg/policies-and-legislation/advance-medical-directive
- Making a Will http://singaporelegaladvice.com/law-articles/how-do-l-make-a-will/

- Central Provident Fund (CPF) Nomination http://www.cpf.gov.sg/Members/Schemes/schemes/other-matters/cpf-nomination-scheme
- Central Provident Fund (CPF) Withdrawal http://www.cpf.gov.sg/Members/Scheme/schemes/other-matters/cpf-withdrawals-on-other-grounds
- Dependency Protection Scheme (DPS) claims http://www.cpf.gov.sg/Members/Schemes/schemes/other-matters/dependents-protection-scheme
- Eldershield (ESH) claims
 http://www.cpf.gov.sg/Members/Scheme/schemes/healthcare/eldershield
- Housing Protection Scheme (HPS) claims http://www.cpf.gov.sg/Members/Schemes/schemes/housing/home-protection-scheme

When to call the cancer care team

If you feel overwhelmed or find that you are unable to cope with your loved one's care, please speak to your doctor or nurse about it. If your loved one is a patient with NCCS, you may also call **+65 6436 8417** or **+65 64368088** to book an appointment with an NCCS medical social worker, to find out more about how they can help you.

If you have any questions regarding the above information, please call Cancer Helpline at **6225 5655** or approach your doctor or nurse for further details.

The above contents are made available as part of TEMASEK FOUNDATION-ACCESS (Accessible Cancer Care to Enable Support for Survivors) PROGRAMME, a holistic care programme to support cancer patients during their care and recovery journey.

The contents have been approved by the Cancer Education Information Service, National Cancer Centre Singapore (NCCS), for people with cancer and their families and caregivers. However, this information serves only as a guide and should not be used as a substitute for medical diagnosis, treatment or advice. For specific medical conditions, please seek expert medical advice from your healthcare team.

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