Palliative Care
Asking the questions that matter to me
This booklet has been developed by the Palliative Care Senior Nurses Network and adapted with permission from Palliative Care Australia “Asking Questions can help – an aid for people seeking the palliative care team.”

This booklet is also available on the All Ireland Institute of Hospice and Palliative Care (AIIHPC) website: The Palliative Hub – Adult
www.thepalliativehub.com

The Palliative Hub – Adult is aimed primarily at assisting people with palliative care needs, their family members, carers and friends and the wider public in understanding what palliative care is and seeks to help filter the wide range of information available on the internet.

There was a recognised need from within the palliative care community, both in the Republic of Ireland and in Northern Ireland, for a dedicated palliative care website to provide general information about palliative care and as a central point that people with palliative care needs, their family members, carers and friends can use to access specific information, such as services offered by organisations.
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**Introduction**

Palliative care focuses on helping you to live well with an illness which is life-limiting seeking to help you achieve the best quality of life as your illness progresses. Often people think that palliative care is just for those who have advanced cancer, but it is just as important if you are living with advancing heart or lung disease, kidney failure and other conditions, for example motor neurone disease and multiple sclerosis. Not everyone who would benefit from palliative care is about to die, some people live with their condition for a long time and have extended periods of wellness. People can move in and out of needing palliative care services as their needs change.

Palliative care supports you and your family, taking into account your emotional, physical, spiritual and financial needs and goals. The type of support available to you will depend on your needs and the services available in your area. Palliative Care can be provided to any age group and in any care setting, including your home. Your GP and community nursing team, your hospital consultant and other health professionals will work together as your team to ensure that your needs are met.

Specialist Palliative care is provided by health professionals trained to help with difficult issues such as managing pain and other symptoms. The specialist palliative care team includes doctors, nurses, physiotherapists, occupational therapists, social workers and trained volunteers. Whilst it is not easy to ask for help at times, it is important that you and your family have as much support as possible because coping alone can be difficult. When thinking about palliative care, it can bring up a number of questions, and often these can be forgotten in the heat of the moment or remembered later after your appointment. The purpose of this list of questions is to help you to gain the information you need about your illness and palliative care. This list can be used as a prompt so you can pick which questions are most appropriate to your situation. Having these questions on paper may assist you in asking the questions that matter to you.
01

About palliative care services and teams
Available care

☐ Will my GP and nursing team be able to recognise when I need palliative care?

☐ Can my GP and nursing team provide my palliative care?

☐ How much help is available to me at home? And who will provide this help?

☐ What does the specialist palliative care service offer that is different to the services provided by the other doctors/nurses that I see?

☐ Who are the members of the specialist palliative care team and what do they do?

☐ Can I see the specialist palliative care team when I am at home and when I am in hospital?

☐ Is it possible for me to be admitted to a hospital, a hospice or a specialist unit to get my symptoms under control and to then go home again?

☐ Is it possible for me to be admitted to a hospital, a hospice or a specialist unit to give my family a break?

☐ How do I access the services offered by the specialist palliative care team?

☐ Will I ever get out of the hospital, hospice or specialist palliative care unit once I am admitted?

☐ Will I still get treatment now that I am receiving palliative services?

☐ Do I need to tell my family that I am now receiving palliative care services?

☐ If admitted to the hospice will I have privacy to talk to my visitors?

☐ Will I be able to see me my visitors when I want to?

☐ Can my pet(s) visit or stay with me in hospital, hospice or the specialist unit?
Contacting the Palliative Care Team

- How do I contact the GP and nursing team when I need them?
- How do I contact the specialist palliative care team?
- In what circumstances can I or should I contact the palliative care team?
- How long will I have to wait to see the specialist palliative care team?
- How often can I contact the team providing my palliative care?
- Is the palliative care service available after hours or in emergencies?
- Will doctors / nurses repeat the information as sometimes I don’t fully understand medical talk?
- What’s important to know before visiting the hospital, hospice or specialist palliative care unit?
- Will I have to pay for my palliative care?

Additional questions / Notes
The relationship between the professionals who provide my palliative care

☐ Which of my health professionals should I contact first if I am unwell or if there is an emergency?

☐ Who will see me on a regular basis from now on?

☐ Does the specialist palliative care team speak to or write to my GP and other specialists about my care?

☐ Will I continue to have the same doctor when being cared for by the specialist palliative care team?

☐ What is the role of my GP if I have been referred to the specialist palliative care team?

☐ Who can help me to work out questions I may wish to ask my other doctors/specialists?

☐ Who can give me advice about treatment options to help inform my decisions? For example whether to stop or start chemotherapy or other treatments.

☐ How do I get back in touch with you if I have more questions?

Additional questions / Notes
Living with my Illness and Treatment
My illness and what to expect in the future

☐ What is going on with my illness?
☐ What are the chances of controlling my illness?
☐ Will the illness progress?
☐ What can I expect in the future?
☐ What symptoms may occur in the future and what should I do if they arise?
☐ Will I be in pain?
☐ Will my pain and other symptoms be controlled in the future?
☐ If I have a syringe driver does that mean I will die soon?
☐ If I am receiving palliative care does that mean I am dying?
☐ What are the worst days going to be like?
☐ What are the best days going to be like?
☐ What should I tell my family?
☐ How long am I likely to live?

Additional questions / Notes
Lifestyle and quality of life

- How can I make the most of my life?
- What activities may help me to enjoy life more? e.g. massage, meditation?
- What can I expect to be able to do?
- How much activity or exercise is too much and how much is too little?
- How important is my diet?
- What kind of food should I eat?
- Would it help if I gave up smoking?
- Can you advise me if and when I can return to work?
- Can you advise me about the timing of the holiday or trip I wish to take?
- Is it OK for me to drive?
- How can I remain close and intimate physically and/or emotionally with my partner?
Physical symptoms

☐ Can you help to control my pain?

☐ What are the different options available for controlling my pain?

☐ If I have other symptoms, what can be done to improve them? (e.g., constipation, shortness of breath, feeling sick, tiredness, sore/dry mouth)

☐ What is the cause of my symptoms?

☐ What are the different options available for controlling my symptoms?

☐ Can you help to control my other symptoms?

☐ What is the cause of my symptoms?
Treatment and Medications

- Please tell me the side effects of any new medication you prescribe?
- What can be done about the side effects?
- Will new medication affect any of my present medications or other medical conditions?
- Are there any tablets that I should NOT take whilst on this new medication?
- Do I have to pay for my medication?
- Can I get the new medication from my local chemist/pharmacy?
- What are all my tablets for?
- Are all my old tablets still necessary?
- What should I do with medicines I no longer require?
- How and when should I take my medication?
- What if I can’t manage to take all my medication?
- Are there any medications or treatment to relieve my anxiety and panic?
- Are there any natural or complementary therapies that may be helpful for me, including herbal treatments?

Additional questions / Notes
Morphine

☐ What are the different ways of taking morphine?
☐ Are there other pain killers or alternatives available?
☐ Will my body get used to morphine if I start it now?
☐ Will it still be effective in the future?
☐ Is taking morphine addictive?
☐ Am I allowed to drive when I take morphine type of medication?
☐ Can I stop taking it if my pain goes away?
☐ Will it make me confused or sleepy?
☐ Will it make me constipated?
03 Support
Support in the form of information

☐ What information is available about palliative care and my illness?
☐ Are books, DVDs or pamphlets available?
☐ Are there any other organisations that may be useful for me to contact?

Practical support

☐ Is there a programme of activities available to me through palliative care or other service? (OT, physiotherapy, massage, spa, breathlessness clinic, day centre)
☐ Can you provide equipment to make everyday living easier at home?
☐ Am I eligible for disability parking? How do I apply for this?
☐ Are there any volunteers available to help me? (to take me to an appointment, or to do the shopping)
☐ How can I provide for my pet(s) in the future when I am no longer able to care for them?

Financial Support

☐ What costs will I have to pay during my illness? (for equipment required or medications)
☐ If I have to pay, is there any way I can get medical equipment for example oxygen or medications at a cheaper price?
☐ What financial assistance is available for me and/or my carer?
☐ Is there someone I can talk to about financial matters?
☐ Do I have to have private health insurance to access palliative care?
Emotional Support

☐ How am I likely to feel through this and what can I do to cope?
☐ How can I deal with anxiety or panic if this occurs?
☐ How can I deal with depression if this occurs?
☐ Is there someone I can talk to about my fears and concerns?
☐ How can I cope with the changes in my body as a result of this illness?
☐ Is it possible for me to talk to a member of the palliative care team alone?
☐ Are there any support groups available?
☐ Can someone help me to communicate with other members of my family about what is happening to me?
☐ What support is available for my partner/spouse, children, relatives, friends?
Spiritual and Cultural Support

☐ Is there anyone that I can speak to about my spiritual or religious needs?

☐ Can you arrange for me to talk with someone from my culture, someone who may understand me better?

If you are concerned about the care you are receiving from a health professional

☐ Can I get a second opinion about any aspect of my palliative care?

☐ Can I choose which hospital or palliative care team I am linked to?

☐ Who can I talk to if I am concerned about the care that I am receiving?

☐ Is it possible for me to see someone else if I don’t get along with my palliative care nurse or doctor? How do I go about this?

Additional questions / Notes

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For Carers

If you have a carer the following questions may be useful for them. Some of the questions listed here may not be relevant to your stage of illness.

☐ What skills do I need as a carer?
☐ Do you think I can look after my partner, relative or friend at home?
☐ Can I get help if I cannot manage?
☐ How can I best support the person that I am caring for?
☐ What should I do if my partner, relative or friend won’t eat very much?
☐ If my partner, relative or friend eats more, will this make them live longer?
☐ How can I assist health professionals to talk to my partner, relative or friend in a way that respects their personality/culture?
☐ Who can I talk to if I am concerned about the care my partner, relative or friend is receiving?
☐ What should I say if my partner, relative or friend asks me “Am I dying”?
☐ What can I do if my partner, relative or friend doesn’t want to talk to me?
☐ What should I do if my partner, relative or friend doesn’t want to know the detail of their illness?

Additional questions / Notes
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End of life issues
Questions that I may like to ask

The following questions may not be relevant to you at your stage of illness. Please do not feel you have to read this section if you don’t want to, but there may come a time in the future when you want to ask some of these questions.

☐ How do I get my affairs in order and write a will?
☐ What does advance care planning mean?
☐ Who can I talk to about the medical care that I want in the future when I am no longer able to speak for myself?
☐ What can I ask my Doctor to do for me when I am very ill?
☐ What is an advanced directive?
☐ What is a living will?
☐ How do I write a living will?
☐ How can I cope when I get sicker and can no longer care for myself?
☐ How can I cope with becoming more dependent on others?
☐ What can I expect in the last days of life?
☐ Is there anyone I can talk to about what happens when I die and the practical issues around organising my funeral?
☐ Will you be able to tell me when it is getting close to the time I will die?
☐ What happens if I go into a coma?
☐ Is it feasible for me to die at home rather than in the palliative care unit, hospice or hospital?
Questions that my carer or family may like to ask

☐ If I cannot manage to look after my partner, relative or friend at home, how can we come to terms with this?

☐ What should I say when the person that I am caring for asks, “Am I dying?”

☐ Will you be able to tell me when it is getting close to the time that he/she will die?

☐ When should I call the rest of the family? What should I say to them?

☐ Could you speak with them for me?

☐ How do I know when my partner, relative or friend has died?

☐ What happens after my partner, relative or friend dies?

☐ What happens to their body?

☐ How do we arrange the funeral?

☐ What support is available for the family after the person dies?
For further copies please email:
info@thepalliativehub.com

or call:
+ 353 1 491 2948

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