



مستشفى الملك فيصل التخصصي ومركز الأبحاث
King Faisal Specialist Hospital & Research Centre
مؤسسة عامة Gen. Org.

Palliative Care Guide in the Outpatient Clinics

The medical team taking care of you

<p>The primary physician: Specialized in treating your primary disease.</p>	<p>Name: General hospital number: 19 9019</p>
<p>The palliative care team: Work in collaboration with the primary medical team who's supervising your health condition, to optimize your wellbeing during the treatment period, by providing help to alleviate your symptoms such as pain, nausea, sleeping issues, and anxiety. They also provide you and your loved ones with emotional support.</p>	<p>Palliative care physician Name:</p>
	<p>Palliative care clinical nurse specialist Name: Telephone: 0112162919 Extension/pager:</p>

Are you experiencing...?

- Unpleasant/difficult to manage symptoms due to your illness or its treatment, such as pain, shortness of breath, fatigue, nausea, etc.
- Symptoms that significantly impact your quality of life and the level of your daily activity.
- Eating problems due to illness or its treatment.
- Frequent need to visit the Emergency Room for recurring symptoms (e.g., pain).
- Difficulty coping with the stress of living with a chronic illness.

Do you need help with...?

- Expectations regarding your illness, treatment plan, and future.
- Understanding the benefits and burden of the treatment options, such as dialysis for patients suffering from kidney failure, supportive tumor treatments, surgical intervention, and radiation therapy.
- Making decisions about the treatment options.
- Matching personal goals and values with medical care.
- Receiving guidance on how to talk to your family about your illness and what is important for you.
- Knowing what programs and resources are available to support you and your family.

It would be useful to be followed-up by the palliative care team to help you get the answers and sufficient information of the above aspects.

What is palliative care?

It is a type of care that focuses on improving the quality of life (wellbeing) of patients with chronic illnesses that might become more severe as days go by, and become life-threatening. Such as tumors, advanced heart/lung/liver/kidney diseases, Alzheimer, amyotrophic lateral sclerosis “which is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord”, multiple sclerosis “chronic disease that affects the central nervous system”, Parkinson disease, and other diseases.

Members of the palliative care team:

- Nursing staff.
- Physicians specialized in palliative care.
- Physicians and specialists in mental health.
- Specialists in physiotherapy and occupational therapy.

- Specialists in clinical nutrition.
- Specialists in patient relations and social services.

Through their expertise, this team can help relieve uncomfortable physical symptoms:

- Pain.
- Shortness of breath.
- Nausea.
- Difficulty sleeping.
- Anxiety.

A palliative care team can also provide you and your family with psychological and social support. You may meet a member from the palliative care team in the treatment area or the outpatient clinic.

Palliative care is an additional layer of comprehensive medical expertise that supports your care.

The essence and concept of palliative care are to maintain your quality of life and work to improve it.

If you want more information about palliative care, please contact the palliative care clinical nurse specialist.

How can palliative care improve your quality of life?

By the following:

- Treating the symptoms, such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, or sleeping disorders.

- Managing your pain in all its aspects. Pain is often more than just mere physical pain. It can be physical, emotional, and social pain. This combination is called “total pain or total suffering”. All sources of pain must be treated to feel relatively stable and thus improve the quality of life.
- Providing you with support about the nature of the terminal illness, regardless of the treatment option you have chosen.
- Making sure you benefit from the resources available to you and your family during and after the treatment.
- Helping you to better understand your condition and your choices in terms of the comprehensive medical care.
- Respecting your choices and beliefs in regards to the disease and treatment.
- Helping you to carry on with your daily activities as well as possible.

How to manage physical symptoms at home?

***If you have severe symptoms, seek medical attention immediately.**

1. Pain:

- Some patients might experience physical pain as a result of their primary disease, or the side effects of the treatments, or other medical conditions. Not everyone will have pain. The pain can be managed through a range of therapeutic interventions, including a system of painkillers of different nature and mechanism of action.
- Depending on the intensity and type of your pain, the doctor will prescribe the correct medication. Each person has a different tolerance to pain and reacts differently to each medication. Your pain treatment plan should be individualized.

- It is important to talk to the medical team about the level of pain, its nature, and the level of response to pain medication.
- When pain persists, it can have a negative effect on your quality of life and ability to continue the treatment.

About opioids “pain medication”:

If you are having physical pain, your doctor may prescribe you “opioids”, such as morphine, fentanyl, codeine, etc.

Opioid analgesics are used to relieve moderate to severe pain. They can be an important part of your pain management plan, but they also carry risks if not used properly and not according to medical recommendations. **These risks are greater in the presence of:**

- Past or current history of drug usage or prohibited substances.
- Mental health conditions such as depression or advanced anxiety.
- Sleep apnea.
- Aging (65 years or older).
- Pregnancy.

Opioids are used to improve and control your pain, and therefore improve your ability to remain active and carry on with your daily activities as high quality as possible.

A pharmacological treatment plan is usually drawn-up by engaging you with the medical team, setting goals through it, and working to monitor the effectiveness of the drug in pursuit of the goal, for example, improving your ability to do the things you were doing before physical pain prevents you.

Opioids require regular calibration and follow-up, and the palliative care team will provide you with scheduled follow-ups, through which the level of physical pain and any physical symptoms that may occur in this aspect, as well as your ability to reach your physical activity goals, are all followed-up.

There are side effects of opioids, but they can often be controlled through appropriate medical follow-up.

Types of pain medication:

If you have chronic physical pain, the pain medication is likely to be prescribed regularly and as needed (if necessary), as this strategy improves pain more efficiently.

- **Regular pain medicine:** it is important to take regular pain medication based on medical advice for optimal pain management, whether you are having pain or not.
- **Pain relief as needed:** a pain medication will be prescribed to take only if you are experiencing severe pain. This medication will act quickly and usually is effective for about four hours. If you require this type of pain medication for more than three doses in one day, then you should discuss it with your physician to see if an adjustment is needed.

Most common side effects of opioids:

- **Feeling sleepy:** it will usually fade away after few days.
- **Nausea:** it will usually fade away after few days. You can ask your physician for anti-emetics if needed.
- **Constipation:** it will be an ongoing side effect during the whole time you will be using opioids, but it can be easily managed with a proper regimen of laxatives. It should not prevent you from taking your pain medication when needed.
- **Dry mouth:** it tends to persist. You can suck small ice chips, take sips of water or candies to reduce it.

If these side effects persist or are causing significant discomfort to you, kindly talk to your primary physician during follow-up

appointments.

If the side effects are significant and can't wait for the next appointment, kindly contact the palliative care clinical nurse specialist.

Be cautious:

- Never take opioids in any amount or other than what was prescribed or agreed upon with your physician.
- Never stop taking the regular opioids suddenly, as you may experience uncomfortable withdrawal symptoms (e.g., nausea, diarrhea, chills). Opioids taken regularly need to be decreased gradually as per the agreement with your primary physician.
- If, for some reason, you have not taken your regular opioids for three days or more, do not restart them without consulting the physician. Your dosage might need to be adjusted for your safety.
- Make sure you have a sufficient amount of opioids to cover the period until the next appointment.
- Follow-up regularly with your physician, and in case you can't attend, kindly inform the palliative care clinical nurse specialist.
- Explore with your team any concerns about opioid side effects.
- Prevent opioid misuse and abuse by never sharing or using someone else's opioids.
- To ensure safety, kindly keep opioids and all medication out of reach of children and people with cognitive deficits.

Other ways to relieve your physical pain:

Explore with your treating team other ways to relieve pain. Some of these options may work better and have fewer risks and side effects.

A combined approach is efficient than using opioids alone.

Other interventions aimed at managing pain include:

- Other types of pain medication, such as acetaminophen, non-steroidal anti-inflammatory drugs (NSAIDs), or even medications commonly used for other diseases (e.g., epilepsy, depression) which have been found to help relieve the pain, especially neurological pain.
- Physical therapy and light exercise, such as: walking short distances without effort.
- Cognitive-behavioral therapy is a psychological, pain-directed approach in which people learn how to modify physical, behavioral, and emotional triggers of pain and stress.
- Relax, attend meditation sessions and yoga exercises if possible.
- Apply warm and cold compresses on the pain site and as recommended by the doctor.
- Massage the pain site when needed and as medically instructed.

2. Nausea and vomiting:

It is recommended to do the following:

- Eat 5-6 small meals a day, rather than 3 large ones.
- Choose food that is not as likely to cause stomach upset, such as plain crackers, rice, cereals, and toast.
- Consume foods and drinks at a moderate or cool temperature. It is tolerated well than hot food.
- Drink plenty of fluids even if you do not feel like it to prevent dehydration.
- Sucking ice cubes is one tip to increase fluid intake when having nausea.
- When feeling nausea, try slow deep breathing with your eyes closed.
- Make sure you do not have constipation; as it can cause nausea. Take laxatives “stool softeners”, if so.
- If you are undergoing chemotherapy, wait at least one

hour before eating or drinking anything after receiving the chemotherapy dose.

- Take anti-nausea medication before meals, if prescribed by your doctor. Wait one hour before eating.
- If you feel nauseated, take anti-nausea tablets when it starts. Do not let nausea get worse.

It is recommended to avoid the following:

- Fatty, spicy, very sweet food, fizzy drinks, and fried food.
- Onions, garlic, coffee, and any foods or drinks that have a strong smell.
- Being around food while being cooked, the odor can make you feel sick.
- Lying down before half an hour after eating.

3. Constipation:

- Drink plenty of fluids regularly (about 2 liters per day).
- If you have heart or kidney disease, ask your doctor which amount of fluids you should drink. It is usually less.
- If you can drink a good amount of fluids per day, then increase natural fiber intake in your diet.
- If you have a narrowing of the bowel or a bowel obstruction, ask the doctor which diet is recommended. Fibers may cause more problems. Examples of food rich in fiber: whole grain, bran cereals, brown rice, lentils, black beans, hummus, pistachio, prune (dried fruit/juice), fresh fruits, smoothies, and Greek yogurt.
- Be physically active.
- Take stool softeners “laxatives”, if prescribed by the physician.
- If you are taking strong medication for pain, such as codeine or morphine, usually physicians prescribe laxatives to take every day.

4. Sleeping problems:

- Avoid caffeine and pre-bedtime stimulation factors, such as: watching TV or using a mobile phone.
- Relax before bedtime by taking a warm bath or shower, meditating, or listening to the Holy Qur'an.
- Go to bed at the same time every night.
- Keep your room cool, quiet, and dark.
- Avoid long daytime naps that can interfere with nighttime sleep.
- If the sleep disturbance persists, talk to your doctor. Sometimes, sleeping medicines can help to solve this issue.

5. Feeling fatigued:

Feeling fatigued is a common manifestation of any incurable disease and a side effect of many treatments as well. Some describe fatigue as a chronic feeling of tiredness. Sometimes, the energy that existed before the disease is not restored once you rest and go to sleep. Feeling fatigued can affect your daily activities.

These are some suggestions that can help reduce the intensity of fatigue and tiredness:

- Distribute your activities throughout the day.
- Set yourself realistic goals. It is OK if you are not as efficient with all your tasks right now.
- Ask for help, such as: preparing meals, picking-up children from school, doing chores, and housework.
- Give yourself some breaks during the day. A balance between the activity and rest is based on your physical and general ability.
- Do light exercises daily, such as walking. This can help to provide you with some energy.
- Make sure to drink and eat well. Dehydration can cause fatigue. If this is difficult, ask to see a dietician.
- Take rests when receiving treatment.

- Avoid taking traditional medicines, herbs, or vitamins to boost your energy before talking to your doctor. These substances can reduce the efficacy of the treatments and damage vital organs such as the liver and kidneys.

6. Loss of appetite:

Good eating habits can help you feel better and stronger if you are receiving therapy, by:

- Increasing your energy level.
- Maintaining your weight and muscle strength.
- Promoting healing (e.g., wound) and strengthening your immune system.
- You might find it difficult to keep-up with the usual recommendations for a healthy diet. Sometimes, the disease or the treatments cause uncomfortable symptoms that interfere with your ability to eat (e.g., nausea, changes in taste and smell). You can ask your physician for a dietician referral.

General tips:

- Eat small portions more frequently. You may tolerate this better than having large meals.
- Keep some snacks with you at all times (e.g., nuts, yogurt, and fruit). When going out such as coming to the hospital, bring them with you.
- Eat nutritious snacks rich in calories and protein, such as yogurt, cheese, eggs, ice cream, seeds, and juices.
- Drink fluids between meals, rather than with meals, to reduce making you feel satiety.
- If you are having trouble tasting food, try adding spices and condiments to make the food flavorful.
- If changes in taste occur, such as a metallic taste in the mouth, try sucking on hard candy such as mints or lemon drops before

eating. Use plastic cutlery. Licorice sweet or licorice tea may also be helpful to some patients.

- If the smell or taste of food makes you nauseated, eat food that is cold or at room temperature.
- Do light exercise, such as a 20-minute walk about an hour before meals, to stimulate your appetite.
- If you are losing weight, ask for a referral to a dietician.

7. Coping with illness:

Since the initial news of an incurable disease comes out, you might be going through lots of emotions and challenges as well as bouts of ups and downs psychologically. You may experience some feelings of fear, anxiety, depression, frustration. This is expected. Nobody is fully prepared for this kind of event. Some days will be more difficult than others. Speak and discuss with the palliative care team, it is very important.

Here are some tips from people who have had a similar experience:

- Do not judge yourself about what you are feeling.
- Share your feeling with someone you trust. Don't keep everything inside.
- Keep praying.
- Write down your diary.
- Set yourself realistic goals. During treatment, you may feel more tired some days. You do not have to keep-up with everything you were doing before you got sick.
- Divide large tasks into smaller ones.
- Ask for help. People around you are often eager to find a way to help you. Give them this opportunity.
- Do not isolate yourself.
- Try to be active such as walking for a short distance.

- Maintain a daily routine such as getting out of bed, taking a shower, and eating as tolerated.
- Engage in activities you normally enjoy, such as reading, cooking, or painting.
- Live your life day by day.
- If you are having a hard day, remind yourself that tomorrow will be better.

Follow-up appointments with the palliative care team at the outpatient clinic:

- - Our clinic is located at King Abdullah Centre for Oncology and Liver Diseases building (7th floor).
- - Please make sure to attend all scheduled appointments to benefit from the medical services offered by the multidisciplinary team.

What should you bring or prepare on the day of the appointment?

- List all your medications, including over-the-counter medicines and herbal remedies (if you are taking them).
- The medication you may be needing during the visit, to ensure your comfort such as pain killers.
- Names and contact information of other healthcare providers involved in your medical care.
- It is often helpful to come with someone else. It can help you remember the recommendations that were discussed during the appointment.
- Remember that you can also write down the information mentioned during the visit.

Who are you going to meet during your

appointment?

You will meet a physician and nursing staff specialized in palliative care. Other healthcare providers might be consulted as well, depending on your needs, such as dietician, social worker, physical therapist, etc.

What will happen during the visit?

- Your health status is generally assessed, as well as physical symptoms, psychological/emotional conditions such as anxiety and sadness, as well as your level of physical activity.
- You will also be asked about other stresses in your life and how your family deals with your illness. In some situations, pharmaceutical intervention might be suggested.
- This visit is designated for you; invest it in identifying what you need by talking to the palliative care team.

What if I cannot come to my appointment?

You can ask a first-degree relative to come on your behalf, or you can reschedule your appointment by calling the palliative care clinical nurse specialist.

During your appointments with the palliative care team, you will be asked to complete a questionnaire, that aims to assess the severity of your symptoms if any, as this will enable the team to better address your symptoms and fulfil your needs.

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