

# **Ivy Grove Surgery**

## **End of Life Care information leaflet**

### **Why have I been given this leaflet?**

Your doctors or nurse may have discussed with you that your medical problems may now be at a 'palliative' stage, or they think you may be approaching the end of your life. This can clearly be a distressing time for you and your relatives. Much of the information in this leaflet will have already been discussed with you. However, we recognise that in these circumstances it can be difficult for people to remember everything that has been discussed during these appointments. It can also be difficult to explain what you have been told to other family members. We hope this leaflet will summarise some of the information you have been given, and can be used as a reminder, if needed. You may have not yet covered everything in this leaflet with your doctor, please feel free to raise any of this information with them if you wish.

### **What is palliative care, and end of life care?**

In essence, palliative care means that a person's medical conditions cannot be cured, or effectively treated. This means the focus of our care changes from trying to cure or manage the medical conditions, to instead, trying to treat any symptoms or problems that arise because of the condition. This includes physical symptoms such as pain, emotional and spiritual distress, and also includes providing help for any practical difficulties a person may be having. End of life care follows these same principles, but this term is usually used when we think someone may only have a few months, or even less time, to live.

Palliative and End of life care can include patients with a wide range of medical problems, and is not limited to just those with cancer.

### **How does Ivy Grove Surgery care for palliative and end of life patients?**

At Ivy Grove surgery, we try to identify patients who we believe are palliative, or approaching the end of their life, to help us deliver the very best care we can to them. We try to do this as soon as possible to allow for Advanced Care Planning (ACP). This essentially means we can identify any potential challenges or problems that might happen in the future, and make a plan about how we can deal with now, rather than have to wait for a crisis. We can also plan for other things such as where the person would like to be when they die, do they need any cares, do they have any spiritual / religious needs.

We will identify a lead GP for your care. This will normally be the GP who knows you best, and has been helping you with your current problems. Please feel free to ask if you are not sure who this is. We also identify a second GP, who will be familiar with the details of your care, should the lead GP not be available. Whenever possible, the lead GP will see you when you need to discuss any new or changing problems, as well as undertake routine reviews of your care from time to time. We hope that this continuity of care will help you and your family feel confident in the doctor who is attending to you, and build a good working relationship. It also makes it easier for us to notice any changes in your condition which may need attention. If your problem is urgent, it may have to be dealt with by the 'on call' GP for that day. Your lead GP will be kept up to date of any developments.

We hold regular Palliative care meetings. These involve the medical staff at Ivy Grove, but also other health care professionals involved in palliative care such as community (district) nurses, and McMillian nurses. We will discuss many of our palliative patients, and all of our end of life patients at these meetings. This allows us to coordinate between the different professionals involved in a

patients care, so that we are all aware of any current difficulties, and can make suggestions about how these can be helped.

We also have two staff members who are attached to our practice. Sue is our Community Matron, and leads the care for many of our patients with long term conditions. Micheala, our Care Coordinator, can help to 'link up' all the different professionals who might be involved in your care, and can also give you advice on any extra services that may be useful to you. We also work closely with the local Macmillan nurses, who have specialist training to help people as they approach the end of their life.

### **What is Do not attempt cardio-pulmonary resuscitation (DNACPR)?**

Cardio-pulmonary resuscitation (CPR) is when trained people, such as paramedics, attempt to keep someone alive when their heart stops and they stop breathing. This usually involves 'chest compressions' and 'mouth to mouth resuscitation'. It is most successful for people who were previously healthy and have a sudden reason for needing CPR, such as a serious accident. CPR is unlikely to be successful for people who are very frail, or have significant medical problems.

When we know that someone is approaching the end of their life, we need to think about what should happen when the person actually dies. Most people who know they are approaching the end of their life, or have a non-curable illness, will want to die in a peaceful, dignified way, in a familiar environment. If such a person's heart stops, and they stop breathing, it therefore may not be appropriate to attempt Cardio-pulmonary resuscitation to keep them alive. Following discussion with the patient and their relatives, we may issue a document which would communicate this to other healthcare workers. This is the DNACPR Document. CPR would then not be attempted if that person dies.

This document is only about CPR, and does not stop you receiving any other medical help you may require.

### **'Anticipatory prescribing' and syringe drivers**

When someone is dying, our hope and aim is that they are as peaceful and comfortable as possible. For a large number of people this is indeed the case, without needing any medical help. However, we recognise that in some circumstances people who are dying can experience some distressing physical symptoms, such as pain or restlessness.

At some stage in that person's care, their doctor might issue them with a prescription for 'anticipatory medications'. This is quite routine, is normally done before any symptoms start, and is not an indication that the doctor thinks that distressing symptoms are going to occur.

We suggest the patient or their family collects the medications from a pharmacy and keeps them in a secure, safe place at home. They may never be needed. However, they will then be quickly available to medical staff, at any time of day or night, should they be needed. They are normally given by the community nurses if needed. They are normally given by injection.

If a person needs to use these medications regularly to control their symptoms, then a syringe driver might be considered. This is a way of giving a small amount of medication continually, which means its effect will never wear off. It is given through a small needle. There is a wide range of medications and doses that can be given, depending on the symptoms that need treating. The medicines given can be changed if the symptoms change.

The particular medications used may be different for each patient; your GP and community nurses will be able to discuss these with you further.

## **Care plan**

At Ivy Grove, we often write a 'care plan' document for patients in some circumstances, including for palliative care. Patients are given a copy of their own plan. This serves several purposes. There may be direct instructions for the patient, such as who to contact for help if your problems worsen, or how to change your own treatment. There may be information for other health care professionals so they can understand your current medical problems (out of hours GPs and hospital doctors can't see your GPs medical notes at present), as well as instructions for the care they should give you. With your consent, we can share these plans with the local out of hours GP service so they can assess the information quickly and easily.

'Care planning' however, is about more than simply providing you with a document. We will encourage you to think about other parts of your future care, such as where you like to be when you die.

You may also wish to consider an 'Advanced Statement' or an 'Advanced Decision' (also known as an Advanced Decision to Refuse Treatment, or a Living Will). In both cases, the idea is that you are able to make known your preferences regarding elements of your care, so they can be taken into account, even if you later become unable to express them yourself. If you would like to consider this further, please discuss it with your GP (however, please be aware you may need to contact a solicitor to produce this document).

Alongside care plans, we also enroll some patients into our 'admissions avoidance' scheme. This aims to identify patients who are at high risk of having a hospital admission or A+E visit, when if possible, it would actually be better to help them to stay at home, with additional support if needed. You may be asked if you would be willing to be enrolled in this scheme.

## **DS 1500**

This can be completed by your medical team if they believe you may be in the last 6 months of your life. Once completed, this can make it much easier for you to apply for certain benefits, such as attendance allowance, and may also entitle you to a higher rate of the benefit.

## **Useful contacts and resources**

Ivy Grove Surgery	01773 514130	<a href="http://www.ivy.gs">www.ivy.gs</a>
Royal Derby Hospital Switch Board	01332 340131	
District Nurse	01773 571460 (or via 111 out of hours)	
Macmillan	0808 808 0000	<a href="http://www.mcmillan.org">www.mcmillan.org</a>
Social Services	01629 533190	
Single Point of Access (SPA)	01773 828 700	
Treetops Hospice	0115 949 1264	<a href="http://www.treetopshospice.org.uk">www.treetopshospice.org.uk</a>

111 for medical help and district nurses out of hours

Some further information from the NHS:

<http://www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx>

## **Ivy Grove Palliative leaflet Feedback**

This leaflet has been newly developed. Any feedback (positive or negative) would be greatly appreciated. Please bring this completed sheet back to reception, for the attention of Dr Smith

Please circle your answer

1. Have you found this leaflet helpful ?

**Yes**

**No**

2. Did you feel you were able to fully understand the information in it?

**Yes**

**No**

If no, which part(s) did you have difficulty with?

3. Did you feel it was appropriate for you to be given this leaflet?

**Yes**

**No**

If no, please briefly explain why

4. Which part was most useful?

5. Is there any other information you think should be in this leaflet?

6. Please leave any other comments in the space below

**Many Thanks**