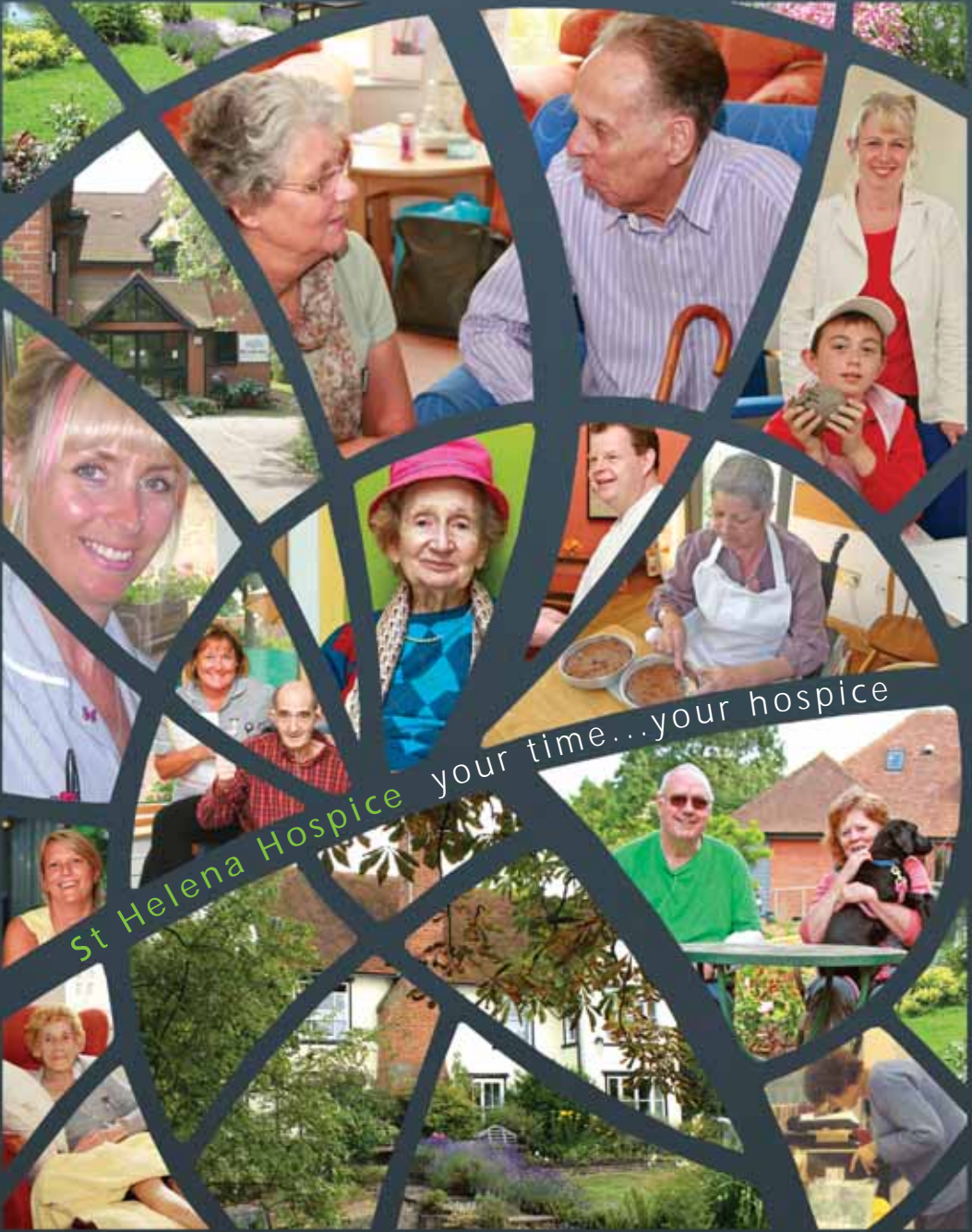


Patient Guide

Issue ^{number} 6



St Helena Hospice your time...your hospice

St Helena Hospice

your time...your hospice



Patient Guide Issue number 6

"We as a family cannot begin to tell you how grateful we are for the exemplary care, compassion and dignity afforded to him from the moment he came to stay with you. The most unbearable time for us was made bearable by every person we came into contact with."

"Thank you for the superb treatment- the love, care, kindness and attention in the beautiful and calm atmosphere of this unique place."

"You were the one service that

- Never had an answer phone*
- Always found me someone to talk to even through the night.."*

"We would like to thank you all so very much for the support, friendship and kindness that you gave to ... and us during his illness."

"...his last few days were made comfortable and dignified. Everything was made available for us no Rules."

St Helena Hospice your time...your hospice

"I will never forget all you did for us; I don't know what we would have done without you and the hospice."

Welcome from Rosy Stamp Hospice Director



You may have opened this information guide with very mixed feelings of anxiety, fear, sadness and perhaps shock if your diagnosis is still new. We will not be able to take away those feelings and the reality of your illness but we will try to ease your journey and walk beside you all the way. We are here not just for you, but for your family and friends and will do our best to support them as well as you.

The philosophy of the Hospice is to work 'holistically', that is to give you physical, spiritual, psychological and social care. We also aim to work with all the other professionals looking after you and ensure that communication and collaboration make your care as co-ordinated as possible.

The services of St Helena Hospice are free to all our patients and families. The Hospice is paid for partly by a grant from the NHS (about a third of our care costs) and the rest is provided through generous support from the local community. If you would like to know more about where the money comes from and how you can help, please refer to the sections on fundraising and volunteering. We are here for everyone from every background and faith who needs our services.

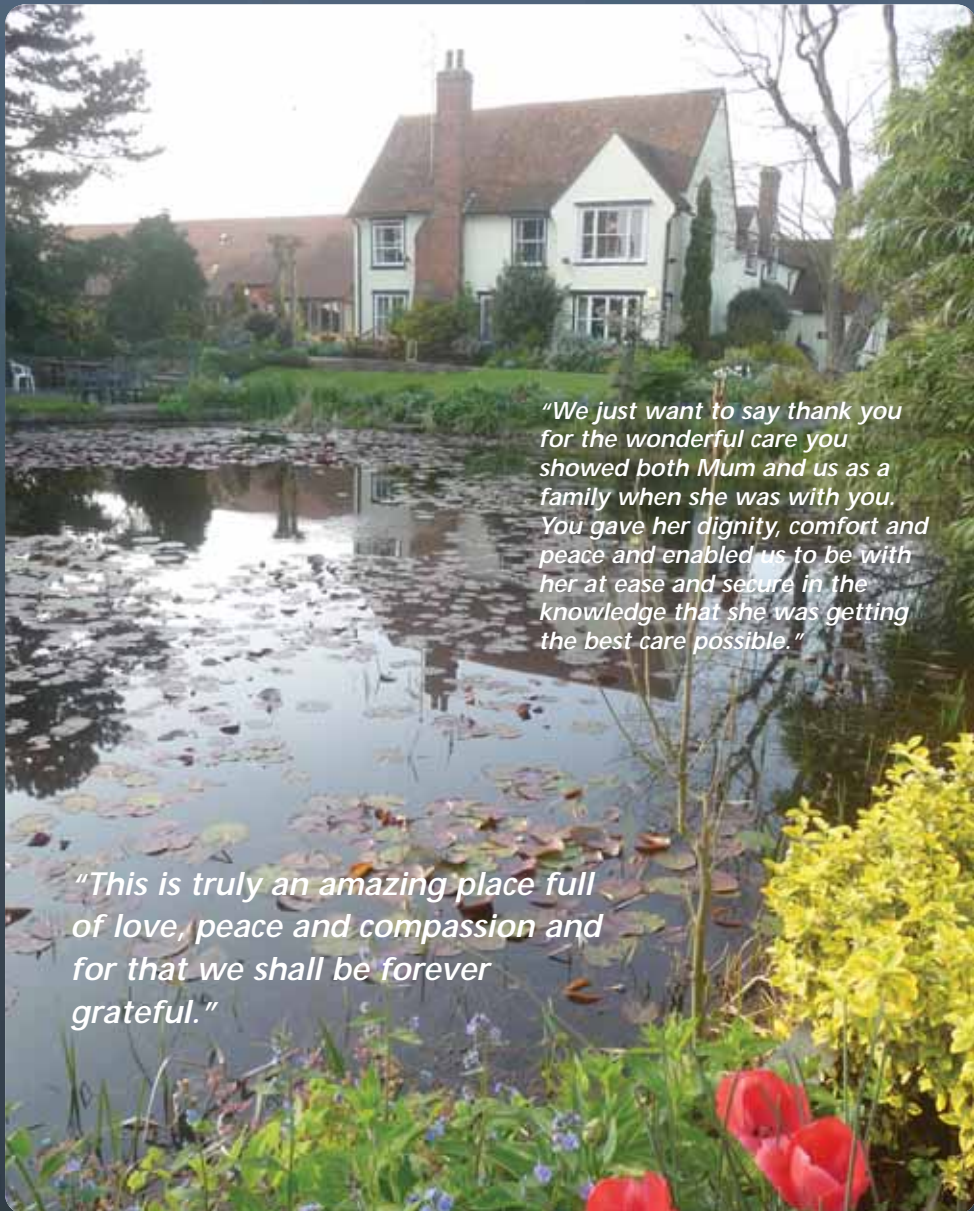
Hospices believe that good care and support can make all the difference to your quality of life. We may be able to help you at any stage of your illness and many of our patients dip in and out as they feel they need us.

Please read through the guide as you feel ready to do so and let us know how we might be able to help you or contact us to find out more.

A very warm welcome from all of us.

A handwritten signature in green ink that reads "Rosy Stamp". The signature is stylized and cursive.

Rosy Stamp Hospice Director



"We just want to say thank you for the wonderful care you showed both Mum and us as a family when she was with you. You gave her dignity, comfort and peace and enabled us to be with her at ease and secure in the knowledge that she was getting the best care possible."

"This is truly an amazing place full of love, peace and compassion and for that we shall be forever grateful."

Contents



Welcome from Rosy Stamp Hospice Director	4
Introduction	8
How can I get help from the Hospice?	9
Day Services	10
St Helena Hospice Nurse Specialists (HNSs)	11
Inpatient Services	12
Medical Services	13
Rehabilitation	14/15
<i>Occupational Therapy</i>	
<i>Physiotherapy</i>	
<i>Lymphoedema Service</i>	
Support Services	16
<i>Library Resources</i>	
<i>Complementary Therapy</i>	
<i>Massage</i>	
<i>Reflexology</i>	
<i>Shiatsu</i>	
<i>Acupuncture</i>	
Counselling, Music and Art Therapy	18
<i>Counselling</i>	
<i>Music Therapy</i>	
<i>Art Therapy</i>	
Spiritual Care at St Helena Hospice	19
Support for Families	20/21
End of Life Support	22/23
<i>Preferred Priority of Care</i>	
<i>The Inpatient Unit</i>	
<i>Resuscitation</i>	
<i>Hospice at Home</i>	
Planning Ahead	24/25
<i>Next of Kin</i>	
<i>Mental Capacity Act 2005 (MCA)</i>	
<i>Children</i>	



Bereavement Services	26
The STARS Programme for Families and Children	27
Volunteers	28
St Helena Hospice Partnership Group	29
Fundraising	30
St Helena Hospice Policy	31
<i>Policies and Procedures</i>	
<i>Complaints, Feedback & Suggestions</i>	
<i>Smoking</i>	
Confidentiality	31
Inspection	32
<i>Access to Hospice Records</i>	
<i>Suggestions about this Pack</i>	
Contact List	33
<i>Day Services</i>	
<i>Community Team</i>	
<i>Inpatient Services</i>	
<i>Bereavement</i>	
<i>Partnership Group</i>	
<i>The Voluntary Services Co-ordinator</i>	
<i>Fundraising</i>	
<i>Library Resources</i>	
How to get there	34
<i>Directions to Joan Tomkins Day Centre, Inpatient Unit, Education Centre, Colchester</i>	
<i>By car from the south</i>	
<i>By car from Clacton</i>	
<i>Public Transport</i>	
<i>Directions to St Helena Hospice, Tendring Centre</i>	35

Introduction



We hope this booklet will help you understand more about the support and services that are available at St Helena Hospice and how you might be able to benefit from them. You will notice that the support is not just for our patients, everyone at St Helena Hospice appreciates that family, or friends, may need help too. Family is taken to include anyone who matters to the patient.

St Helena Hospice is based at Highwoods in Colchester but also has a Day Centre in Clacton as well as a presence in Halstead.

You do not need to be resident at the Hospice to obtain help, as the Hospice operates Day Centres and can bring some of the services to your home if that is better for you.

Many of the people that use the Hospice are experiencing a good quality of life and may, for the most part, be coping quite well. The Hospice can be used as and when their services are needed and you may find yourself using them quite extensively initially and then months or years may pass before you feel the need to return, and that is fine.

We know you are likely to have questions about the Hospice so we have included the most frequently asked questions (FAQs) throughout this guide. If your query is not covered here you can contact St Helena Hospice by telephone 24 hours a day every day of the year.

"It was such a traumatic time with the sudden terminal diagnosis and we didn't want to be apart. We are so grateful to the whole Hospice at Home team for making this possible for us."

"Thank you for the superb treatment, the love, care, kindness and attention in the beautiful and calm atmosphere of this unique place", (patient quotes, 2011)

"My Mother sadly died at the Hospice on July 1st but I know that for the final nine days of her life she could not have had better care or a nicer environment to be in."

"I'm sure we speak for thousands of other relatives who have lost dear ones but have been comforted throughout by the dignity and care provided"

(quote from 'thank you' card, 2011)

How can I get help from the Hospice?



There are several ways you can be referred to the Hospice, the most common are by your GP, by a district nurse, via the hospital or by some other professional dealing with your condition. You can even contact the Hospice yourself if necessary.

After an initial assessment, the team will work with you and your family to agree a plan that will form the basis of our support, which is then reviewed on a regular basis. For example, this support might take the form of home visits or it could be that our Day Service is a more appropriate support (more of this later).

The Hospice team provide 'palliative care' which is a term that you will hear a lot. The team consists of people from many specialist areas that come together to offer support and comfort to you and your family or carer; not all of them from a medical background but all dedicated to helping you get the most out of life. You will find a description of the main areas in this guide.

FAQ - *What does 'palliative care' mean?*

Here is the definition given by the Government guidelines:

"Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families."

FAQ - *Does the Inpatient Unit offer respite care?*

The Hospice does not offer social respite as this is provided through health and social services. However the Inpatient Unit can offer admission for the patient and a break for the family when there are complex psychological or physical issues that only an inpatient stay can address.

Day Services



St Helena Hospice operates two Day Services Centres, at the Joan Tomkins Centre in Colchester and the Tendring Centre in Clacton, that benefit a large number of people in the surrounding areas. The Centres are the bases for highly skilled teams offering specialist information, interventions, support and advice to people diagnosed with a life-threatening illness as well as working with their family, friends and carers.

The aim of the team is to work with you and your family to make a plan to enable you to live your life as normally as possible, and to pre-empt any problems that may be approaching. The Day Services teams work alongside their colleagues in the Community and Inpatient Unit to help you make the most of your life at any stage of your condition.

So, you may ask, what do patients actually do when they attend our Day Centres? The following are just some of the activities patients enjoy: massage, chiropody, fatigue management, reflexology, manicure, hairdressing, gardening, Jacuzzi, trips out and just talking with friends and colleagues. Most people who visit our Day Service Centres gain immense support from spending time with others who are living in similar circumstances. Many people attend on a regular day each week, others on a more flexible basis. Transport can be arranged for patients who have difficulty getting to the Day Centres.



St Helena Hospice Nurse Specialists (HNSs)



St Helena Hospice Nurse Specialists are experts in pain and symptom control. They give emotional support and practical advice to patients and families from diagnosis onwards and provide this support through home visits.

As a patient at the Hospice you will have an initial assessment to see if you would benefit from the services of an HNS and this will be re-evaluated as your needs change. The HNS is often the patient's main point of contact and acts as a link between all the health and social care professionals working with you within the Hospice and externally. They can offer advice and access to other services, such as occupational therapists or counsellors (which may be offered at the Hospice), but they will liaise with your GP and Social Services too. They have regular meetings with the hospital oncology consultants to discuss treatment issues and often take questions asked by their patients to these meetings.

FAQ - Can the Hospice Nurse Specialist change my medication?

Yes, they do advise GPs and make suggestions as to which medications might be most suitable for people who are suffering from symptoms such as various types of pain, nausea, constipation and other conditions that may arise. The GP is involved in the decision making process and is ultimately responsible for prescribing the medication

FAQ - Does the Hospice Nurse Specialist have to tell my mother she has cancer?

Sometimes families are informed of the diagnosis and prognosis of a patient without that person being involved. As specialist palliative care nurses, HNSs acknowledge the concerns of the family and recognise that they are only trying to protect their loved one. However, if the patient asks, they will tell them what is wrong in a gentle but honest manner.

They are always led by the patient although they recognise and take into consideration the family concerns. Very often the patient already knows that they have cancer but have also been trying to protect others by not discussing it.

Inpatient Services



Some patients, perhaps with an issue over symptom control or who have specific problems, may be best helped by a short stay in the Hospice Inpatient Unit (IPU). Problems may be physical in nature, such as pain or nausea, and the emphasis is on 'sorting out' symptoms so that patients can go home as soon as possible with the support of our community teams. Patients may need emotional or spiritual support and sometimes this will be the specific reason for admission.

Our aim is to provide specialist care and support for patients in a relaxed and friendly setting. Families, children, friends and pets are warmly welcomed (there is even a resident cat, Charlie, that loves people to make a fuss of him) with open access visiting, if this is what the patient wishes. Meals are prepared on the premises, fresh every day and every attempt is made to cater for dietary requirements. This support is also offered to families, friends and carers of the patient who often comment that 'nothing is too much trouble', when it comes to the care and attention given by the staff and the many Hospice volunteers. The emphasis in every circumstance is on 'living' and improving patients' quality of life.

The Hospice unit is set in beautiful grounds and can accommodate up to 15 patients in its spacious four-bedded bays and single rooms with en-suite facilities, overlooking the gardens. There is also a bedroom available for relatives to stay overnight if they wish and many of the rooms have comfortable chairs that carers are welcome to sleep in.



Medical Services



The medical team has much experience working with patients with life-threatening illnesses regardless of the diagnosis. They work in all areas of the Hospice, seeing patients on the Inpatient Unit, at outpatient clinics and in their own homes. They also see patients in the hospital. They provide specialist advice on the control of symptoms such as pain, nausea and breathlessness and also provide advice out of hours to patients, families and other healthcare professionals.

Like the Hospice Nurse Specialists, the doctors are in contact with the doctors at the hospital and with your GP so that everyone is kept updated on your care.

The medical team are committed to their own continual professional development, through reading of journal articles and attending relevant courses and conferences. They practice evidence-based medicine and are involved in teaching to colleagues at the Hospice and other educational meetings.

FAQ - *Do the doctors just deal with cancer?*

No, they have an expanding role in all advancing and progressive, life threatening diseases; including heart failure, chronic lung disease, motor neurone and other neurological disease, renal failure and HIV and AIDS.

FAQ - *I am worried about taking morphine, will I become addicted?*

Used properly, and in the right circumstances, morphine is an extremely effective pain killer with a long history of safe use. There is no risk of addiction when used properly. Side effects may be short-term or respond to simple treatment and alternatives exist if morphine is not tolerated or is ineffective.

FAQ - *How long have I got left, doctor?*

This is an extremely difficult question to answer accurately and often we have to admit that we don't know. It is influenced by the rate of progression of a disease, response to treatment and the presence of other medical problems.

We are honest and answer the question frankly, balancing realism and hope. We aim, working with our colleagues, to make sure that the patient makes the most of the time left, that distressing symptoms are minimised and that the patient and family are supported up until death and during bereavement.

Rehabilitation



Rehabilitation is about helping a person to stay as independent as possible and to cope with the way their illness affects everyday life. The Hospice wants you to stay as well as you can and remain in your own home but sometimes that does mean that a few assessments and adjustments have to be made to enable you to remain independent and safe. This support is carried out by a range of professionals, in particular, our Occupational Therapist, Physiotherapist and additional support from a Rehab Assistant. A lot of people assume that rehabilitation is just about equipment, for example a bath lift or walking frame, however professionals involved in rehabilitation use a whole variety of skills to encourage independence.

Occupational Therapy

Occupational Therapy (OT) is concerned with how an individual carries out their day to day activities, such as earning a living, personal care or leisure and social activities. They may provide equipment, however they will also advise about different ways of doing things and other ways of coping, for example dealing with tiredness or fatigue.

Occupational Therapy can provide individual help or run courses for small groups to help patients with, for example, body image problems, fatigue management, breathlessness, anxiety and relaxation. The aim is always to promote independence.





Physiotherapy

Physiotherapy looks at ways of addressing physical problems affecting day to day living such as weak muscles or breathing problems. This may include 'hands on' therapy and advice on exercise, positioning, breathing techniques or moving and handling.

Like OT, Physiotherapy's aim is to promote and maintain your independence. Much of the help will be to assist your carers to help you and this can reduce much of the anxiety felt by carers, afraid that they are doing the wrong thing.

The physiotherapist can help pain relief through the use of TENS** , massage, positioning, use of heat and cold and provision of neck collars and splints.

Lymphoedema Service

Lymphoedema is a term used to describe chronic swelling that can occur anywhere in the body, but most commonly affects the limbs. It may be due to an outside source such as surgery, removal of lymph nodes, radiotherapy, cancer itself, or due to a severe infection. While lymphoedema is incurable it can be successfully managed and treatment aims to improve and control the swelling.

The North Essex Lymphoedema Service (NELS) team offer practical support and advice on the management of lymphoedema. It operates out of St Helena Hospice and holds clinics in Clacton and Colchester.

Patients can be referred by their GP, Cancer Nurse Specialist or any other member of the healthcare team or can refer themselves by calling the team on 01206 848168.

Website: www.sthelenahospice.org.uk/northessexlymphoedemaservice.cfm

** commercially available equipment for pain relief

Support Services



The Hospice understands that sometimes it is the little things that get you down, like feeling negative or tired, and not always the big issues of your diagnosis. Often it is the worry over how the family is coping with your illness, and its impact on them, that concern you the most. Various support services are here to help.

Library Resources

St Helena Hospice has an extensive library of resources that patients and their family/carer can use to find information about their condition, medications, support services etc. There is a librarian who will assist with finding what you want and, if required, can guide you to the NHS Choices website which contains a lot of useful information. The libraries are in the Education Centre at Colchester and the Information Centre in Clacton. See Contact List (pg 33) for details

Complementary Therapy

The use of complementary therapies in palliative care is growing as research has shown that its use, alongside conventional medicine, can help enhance relaxation and well-being as well as help with the management of specific symptoms such as breathlessness, nausea and pain control. There are four therapies offered at St Helena, they are:

Massage

Massage is the oldest form of medical treatment known to man. Massage is used to relieve muscle tension, help the body relax and promote a feeling of well being.

Reflexology

This is a therapy which works by the application of pressure to various points on the feet. It is suggested that the application of this pressure in a certain way can enhance general well being and give a feeling of deep relaxation and calm.



Shiatsu

The literal meaning of shiatsu is 'finger-pressure' and its practice dates back several thousand years. Shiatsu is given with the receiver remaining fully clothed and either lying on a futon on the floor, on a couch or sitting in a chair. Research has reported that some of the benefits are better concentration, higher energy levels, improved physical capability and enhanced symptom control.

Acupuncture

Acupuncture has been practised for many centuries and involves the insertion of very fine needles at specific points on the body. These needles stimulate the body's natural responses and can promote general well being as well as aid specific complaints such as breathlessness, pain control and nausea and vomiting.

"You were the one service that:

- Never had an answer phone*
- Never made an offensive comment like 'Treasure each day'.*
- Always found me someone to talk to even through the night."*

(patient comment 2011)



Counselling, Music and Art Therapy



You may find, like many people, that you need time to come to terms with a life threatening diagnosis and need emotional support as well as medical help. Your family too may want the opportunity to talk to someone other than a relative and so this help is available for patients and their carers. Counselling, music and art therapy offer different ways to engage in, express and explore the feelings and thoughts raised by the individual's experience. Starting with an assessment, which gives both the therapist/counsellor and the individual the opportunity to see whether further sessions would be appropriate, confidential, weekly sessions continue in blocks of six and are then reviewed by the individual with their therapist/counsellor.

Counselling

Counselling is an opportunity to talk about and explore issues and emotions that may not be shared with family, friends or in any other setting, in a non-judgemental atmosphere. Counselling is not about giving advice but helping the individual find their own answers and possibly a way to deal more comfortably with what is happening.

Music Therapy

Music Therapy uses music to support communication and expression. Music is a powerful medium which can affect us all deeply and when words seem inadequate or impossible, music can often make sense. In a music therapy session mainly improvised music is used, providing an immediate and personal form of communicating and understanding. A range of accessible musical instruments are available and no musical skill or experience is needed as there are no 'right' or 'wrong' notes in music therapy.

Art Therapy

Art Therapy is not about artistic ability and you do not have to be good at art to do art therapy. Through the use of art materials within a supportive relationship, thoughts and feelings that may be too intense or painful to put into words can find expression. Art Therapy offers the individual a chance to explore emotional and psychological needs at his/her own pace.



Spiritual Care at St Helena Hospice

For some people faith is an important part of their lives whilst for others religion has no significance or relevance whatsoever. At St Helena Hospice we are committed to providing spiritual care for all, irrespective of people's beliefs or lifestyles. The chaplain and all members of the chaplaincy team are pleased to provide a 'listening ear' and spiritual support, and can be contacted through any staff member

For those who are religious, chaplains from various world faiths are available and can offer specific rites, rituals and customs. Christian care includes prayer and bedside communion.

A 'Quiet Room' is available for patients, family and friends, and is open 24 hours a day as a place of peace and quiet reflection. It contains the Books of Remembrance.

FAQ - *What is 'Spiritual Care'*

Spirituality includes everything that gives a person meaning, worth and value. The modern hospice movement is based on the premise that we are more than just physical beings; there is something deep within us that we might call a 'soul' or a 'spirit' that makes us the people we are. Many people who come into the hospice have spiritual pain which may be verbalised in the following types of question...

"Why has this happened to me?"

"What is the point of all this?"

"Is there any meaning or purpose to my life?"

"Am I being punished for past mistakes?"

"Why is God allowing me to suffer?"

FAQ - *What do the Chaplains actually do?*

Chaplains offer confidential and non-intrusive support to both patients and families.

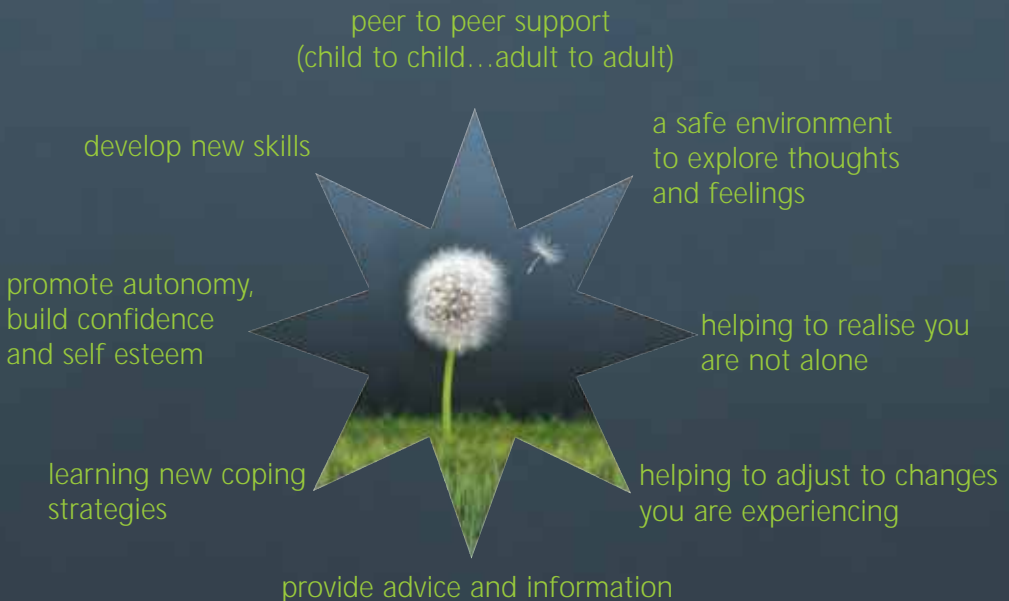
They offer no easy or 'off the peg' answers, but are willing to offer one-to-one care and walk beside a patient on a journey of self discovery.

Support for Families



The Hospice is as much about helping your family and loved ones as it is about caring for you. After all, if you know that your family/carers are coping, this will help you too. Much of the help offered to you is available for your family as well, such as discussing illness and treatments with the children, putting together a memory box / book and preparing family members for the death of someone close.

The Psychosocial team offers a range of services to support adults and children who have a link with the Hospice. 'Family' is a term that includes anyone who matters to the patient. Psychosocial workers include Social Workers, Counsellors, Art and Music Therapists and Family Support Workers and all have similar aims, which are:





FAQ - *I am too unwell to work and I haven't got any money coming in, what can I do?*

The state benefit system can seem complicated and confusing, especially if you have never needed to use it before. This often means that people who are unwell are not claiming all the benefits they are entitled to. Our social workers will be able to provide you with information, assistance and contacts about this.

'I will never forget all you did for us. I don't know what we would have done without you and the hospice.'

(patient quote 2011)



End of Life Support



There will come a time when those living with a life-threatening illness must come to terms with the fact that the end of life is near. The Hospice can offer much needed comfort and support at this upsetting and stressful time. It is not at all uncommon for people to find it impossible to think about practical issues at such an emotional period yet there are practical matters to be considered. Some of the key issues are explained in this section but a more detailed booklet is available on request.

Preferred Priority of Care

Preferred priority of care came into being in 2006. It is a nationally recognised document, which hopefully will ensure that patients are cared for in their preferred setting in the last weeks/days of life. Many people wish to remain at home but, in the past, have experienced difficulties when professionals came to the house and felt hospital was more appropriate.

People can complete the preferred priority of care document when curative treatment is no longer an option. The community healthcare teams have had training in how to complete the document so can help if necessary. The ambulance service recognise the document, so if they are called to the house by professionals and the family produce the document they will adhere to the person's wishes. In the event someone wishes to be cared for in another setting such as the hospice, bed availability has to be considered when the time comes.

The Inpatient Unit

There are many reasons why patients may prefer not to die at home and the Inpatient Unit may be able to offer supportive care at this time. While a bed cannot be guaranteed, the Day Service, Community, Inpatient and Hospice at Home teams work closely together, particularly at the end of life, to try to ensure that patient's preferences are respected.

Resuscitation

There is evidence to suggest that for most terminally ill patients, especially for those with cancer, the probable harm of attempting cardio-pulmonary resuscitation (CPR) outweighs the possible benefits. Most patients cared for by St Helena Hospice will not benefit from attempting CPR although there are exceptions to this.



The medical staff may discuss this with you and, should you wish, with your family. However we recognise that resuscitation is a delicate and difficult subject to discuss and the medical team are always sensitive to the fact that some patients would like to discuss the issue while others may not. There is a helpful information leaflet that staff can give you and one of our senior doctors will be happy to discuss any questions you may have.

Whatever the decision, it will be formally recorded in the hospice notes and a form documenting the decision offered to you. Do not hesitate to tell the medical team if you have any questions or concerns.

Hospice at Home

It is recognised that most people want a good death, a tranquil, pain-free passing in their own homes among the ones they love. St Helena Hospice provides a service that supports people at home at the end of life. This is intended to give patients and carers practical and emotional support so that a patient who wishes to die at home can choose to do so. The service is very flexible and aims to respond quickly to individual patient's needs. Referrals for the service are made through the Hospice or hospital discharge teams, District Nurses, Hospice Nurse Specialists, the End of Life Care team or GPs. The Hospice at Home team members are trained and experienced in palliative care and can help you to maintain your peace and dignity.

FAQ - Will my GP still be involved in my care?

Your local doctor will continue to prescribe medication. The Hospice at Home team is there to provide practical and emotional support and will work closely with the GP, district nurses and Hospice Nurse Specialist. Any changes to care will be in consultation with the GP.

FAQ - Does the Hospice at Home team take over from the district nurse?

No. The district nurse will continue to be the patient's 'key' nurse and the Hospice at Home team co-ordinator will plan with the district nurse when any extra care is needed.

FAQ - How do I contact the team?

Once you are involved with Hospice at Home, the contact number can be found on the front cover of the district nursing notes or you can contact the team through the Hospice.

Planning Ahead



You may already have made arrangements to secure the future for the significant people in your life but for many people making Wills, financial planning, pensions and making funeral arrangements are things that they may not have done before and they need help. Living together, divorce and children can make matters more complicated as issues around next of kin and responsibility for children are complex. So for some people it may be helpful to think again and take advice if they have any anxieties.

Next of Kin

Before a death it is possible for a patient to appoint any person of their choice to be recognised as their next of kin, whether or not they are related. However, after a death this person will not be legally recognised if there is a direct living relative or spouse. We would advise patients to consult a solicitor for guidance.

Further information is available on: www.advicenow.org.uk/livingtogether
Mental Capacity Act 2005 (MCA)

This Act came into force in 2007 and creates important new safeguards for anyone who, through illness, injury or disability, has difficulty making decisions. If this is applicable now or you would like to plan ahead in case it happens in the future, then this Act will be of interest to you. Please ask a member of the Hospice staff if you would like more information.

Children

In situations where children are living with their mother (the patient) and their biological father is estranged from their mother, or is the mother's partner, there should be documented evidence of how the mother wants her children to be cared for after her death. It is not sufficient to assume that a written request (or a Will) is adequate or to assume that the children's biological father can continue caring for the children.

Children born prior to December 2003 - If the biological father is not married to the children's mother he does not have parental responsibility in



the event of her death, even if his name is on the birth certificate. Children born after December 2003. In the same circumstances the biological father would automatically have parental responsibility if his name is on the birth certificate.

In such circumstances we advise patients and families to consult a Family Law solicitor who is familiar with the Children Act to ensure that arrangements made for children are legal and binding. The mother can make other arrangements, but only by a legal process. Any local solicitors firm can give you a list of local Family Law solicitors.

Planning like this as far ahead as possible ensures that your wishes are carried out and we can help you get access to information and the contacts to make your arrangements.

If you wish to discuss any of the above please contact one of the Hospice Social Workers.



Bereavement Services



Emotional support is perhaps the first and most obvious need that family and friends struggle with when someone close to them dies. Support from the hospice usually starts with an initial telephone contact and may lead to home visits and individual grief counselling, if appropriate. Consultation and advice is also available to other professionals and organisations, including schools.

The St Helena Bereavement Service has counsellors, social workers, therapists, chaplains and bereavement volunteers available to ensure the most appropriate help can be offered. Grief Support Programmes are also provided to lessen the isolation of newly bereaved families, children and grandchildren.

The person who is left may have little practical experience and it is the loss of help with the mundane aspects of life that can make the grief all the harder to bear. 'Link' meetings, a support group for the newly bereaved, are held monthly at the Colchester and Tendring Day Centres and provide an opportunity to meet and talk to others in a similar situation.





The STARS Programme for Families and Children

This is specifically run to help the particular needs of surviving parents with children, from young children of five to young adults up to twenty-two years. The programme takes place at least once a year and families will usually have been bereaved for at least 6 months after a death before attending the group.

There is a separate leaflet available but, briefly, the programme aims are:

Supporting families in coping with the death of someone special.

Talking to other people who have had a similar experience to lessen the sense of isolation.

Aadjusting to the changes that families face after the death of a parent.

Remembering the person who has died through a range of creative and expressive activities.

Someone special; someone unique. Feeling you are not alone and feeling ready to move on.



Volunteers



Volunteers not only contribute a great deal of manpower at the Hospice but bring skills, interests and individual experiences to the patients. There are over 900 volunteers filling more than 60 roles so there is bound to be something to suit everyone. Volunteers come from all walks of life and commitment, reliability, commonsense and flexibility are just some of the qualities which are needed.

Some but not all duties which volunteers carry out will bring them into direct contact with patients or their families. Satisfaction in volunteering is all about matching skills, interest, passions and personality with available opportunities.

FAQ - *Why do people volunteer?*

There are many reasons why people choose to get involved. These are just a few:

To support the Hospice's work

To do something unusual and inspiring

To meet people and make new friends

To learn new skills and expand their CV

However, the response given by most of our volunteers about why they do it is quite simply because they find it enjoyable and rewarding.

FAQ - *How much time do I have to give?*

Most roles usually involve a morning, afternoon or evening duty, although there are some exceptions with greater flexibility. You can volunteer for a weekly, fortnightly or 1 week in four duty; this will depend on the time you can afford to give. It is far better for a volunteer to begin modestly and perhaps increase the involvement later.

FAQ - *How do I get involved?*

Please contact the Voluntary Services Co-ordinator (details are on page 33) and we will give you an information pack containing details of our current vacancies and an application form. We will also be delighted to answer any questions that you may have.

St Helena Hospice Partnership Group



The Partnership Group is a group of patients and current and previous carers who advise the Hospice management on any user-related matters. The group uses its experience to provide feedback on potential changes and to propose enhancements to existing services and facilities. In fact this Patient Information Pack was produced by this group.

The Group members organize and carry out the annual patient survey and report on the results to the Hospice managers and trustees. They have also produced a Visitors Guide which provides useful information about the Hospice for new visitors. The Hospice management is very supportive and consult the Partnership Group on a wide range of topics.

The Group meets on a Saturday morning at the Hospice. New members are always welcome, see page 33 for the contact details

FAQ - Who can join?

Anyone who has experience of using the Hospice services, either currently or in the past. This includes patients, carers, friends and/or family members.

FAQ - How often, and where, do you meet?

The group always meets on a Saturday morning at the Hospice in Colchester. We meet as often as necessary for the work we are doing but it is usually about once a month.

FAQ - I'd have difficulty getting to meetings. Can you help?

Group members give their time freely but are not expected to be out of pocket when attending meetings. Reasonable travel costs are reimbursed and special arrangements can usually be made if a member has particular difficulties getting to meetings. A member can also contribute to the group by e-mail, letter or by telephone. Expenses are paid from the NHS user participation budget; they are not taken from Hospice funds.

Fundraising



All St Helena's services are free to patients and their families. As a registered charity, we have to rely upon the generosity of our community to provide financial support for the work to continue.

It costs over £5.6 million a year to provide Hospice services, which are available to over 380,000 people in our region. Funding comes from a range of sources including; legacies, funds raised by our shops, events, our own lottery, donations from individuals as well as local businesses and support provided by grant making bodies. We are not part of the NHS but we do receive a grant from our local primary care trust (PCT) which contributes towards some of the services we provide to the community on their behalf.

Every penny donated to St Helena Hospice really can make a difference. We would like to be in the position of not just maintaining current services but to help more people in the future by expanding our services. For this to happen we need more donors. We also need to constantly improve our facilities and equipment for patients and families, ensuring that we provide the best clinical standards and care. Some of these improvements are expensive but are also vital. Can you help us with these costs? If you would like to support St Helena Hospice or would like further information, please contact the fundraising team; details are on page 33.

FAQ - *How do you handle specific donations?*

Sometimes donors have very specific views as to how they would like their money spent. When this is the case we receive the donation into a Restricted Fund and monitor it to ensure that it is only spent in line with the donor's wishes. Sometimes we receive money that we are unable to spend because of the restrictions applied to the donation. In that situation, rather than holding the money in our bank accounts, we will contact the donor and discuss with them the possibility of using the money for a slightly different purpose, more in line with our current requirements.

FAQ - *Why is Gift Aid so important to St Helena?*

If you are a UK taxpayer, Gift Aid offers a simple way to increase the value of your gift to Hospice by allowing us to reclaim the tax on your gift.

St Helena Hospice Policy



Policies and Procedures

All policies and procedures are available on computers throughout St Helena Hospice. If you would like help accessing these or copies of any of them, please ask any member of staff.

Complaints, Feedback & Suggestions

The Hospice aims to bring you the best specialist service possible. If any part of your experience is above or below expectations, we would like to hear about it. Our Complaints Policy and Procedure and Feedback/ Suggestion Forms are available in every department. Please do not hesitate to use them. Alternatively, you may approach any member of staff to make a comment, positive or negative. All complaints, feedback and suggestions will be used anonymously, if this is the person's wish. From time to time we ask patients to contribute to questionnaires and surveys and patients have a right to see the reports written from these.

Smoking

It is now illegal for any employee, volunteer or visitor to smoke within the Hospice buildings. There is a designated area outside where smoking is allowed. Patients, however, may smoke in the smoking room within the Inpatient and Day units.

To protect the health of our staff we always ask patients and family members to refrain from smoking during a home visit by any Hospice representative.

Confidentiality

Information received by Hospice staff from patients and families will be managed appropriately with regard to confidentiality and the privacy of individuals. Individual patients will be provided with information on their diagnosis, prognosis, treatment and care options, to the extent that the patient wishes to have this information. With the patient's stated permission, carers and families will also be provided with this information.

Looking After Your Information

All staff members are trained in their responsibilities in maintaining good information management and security. The Hospice recognises the need for an appropriate balance between openness and confidentiality regarding the management and use of information. However, it is a patient's right to request access to their Hospice records. Patients should ask any member of staff and this will be actioned in line with St Helena Hospice's policy and procedure.

Inspection

St Helena Hospice is regularly inspected by its regulatory body, the Care Quality Commission.

Their address is:

Care Quality Commission
Finsbury Tower
103-105 Bunhill Row
London
EC1Y 8TG
Telephone: 0207 448 9200

Patients are interviewed as part of this process.
Copies of Inspection Reports are available at the Hospice and on the Care Quality Commission website at: www.cqc.org.uk

Suggestions about this Guide

This Patient Information Guide is reviewed annually to ensure that the information in it is up-to-date. If you wish to make comments or suggestions about this guide, please ask for one of our Feedback / Suggestion Forms which are available in all departments of the Hospice.

This **guide** was produced November 2011
Next review November 2013

Contact List

Day Services

You can contact us
Monday-Friday between 9am and 5pm at:

Colchester / Halstead Day Services

01206 848163

Tendring Day Services

01255 221222

Community Team

You can contact us
Monday-Friday between 9am and 5pm at:
Colchester/ Halstead Community
Telephone 01206 845566
Tendring Community
Telephone 01255 221222

At weekends and bank holidays between
8.30am-4pm, a Hospice Nurse Specialist is
available for advice and can be contacted
on 01206 845566

The Hospice can give advice outside of
these times on 01206 845566

Inpatient Services

You can contact us 24 hours a day,
7 days a week on:
Telephone 01206 845566

Bereavement

You can contact us
Monday-Friday between 9am and 5pm at:
St Helena Hospice
Tendring Centre
Telephone 01255 221222
St Helena Hospice
Telephone 01206 845566

Partnership Group

Contact-Ken Aldred (Chairman)
Tel: 01206 751397
or St Helena Hospice reception
Tel: 01206 845566

The Voluntary Services Co-ordinator

St Helena Hospice, Myland Hall,
Barncroft Close, Highwoods, Colchester,
Essex. CO4 9JU
Telephone 01206 845566
Website: www.sthelenahospice.org.uk

Fundraising

If you would like to write or visit the team,
the fundraising office is located at:
St Helena Hospice Fundraising Office,
95-97 Magdalen Street, Colchester.
CO1 2LA
Telephone: 01206 791740

Library Resources

St Helena Hospice, Education Centre,
Barncroft Close, Colchester CO4 9JU
Telephone 01206 851560
e-mail: edcentre@sthelenahospice.org.uk

Tendring Centre, Jackson Road
Clacton-on-Sea CO15 1JP
Telephone 01255 221222

How to get there



Directions to: Joan Tomkins Day Centre,
Inpatient Unit, Education Centre, Colchester.

Please refer to the map below for our location in the town.

By car from the south

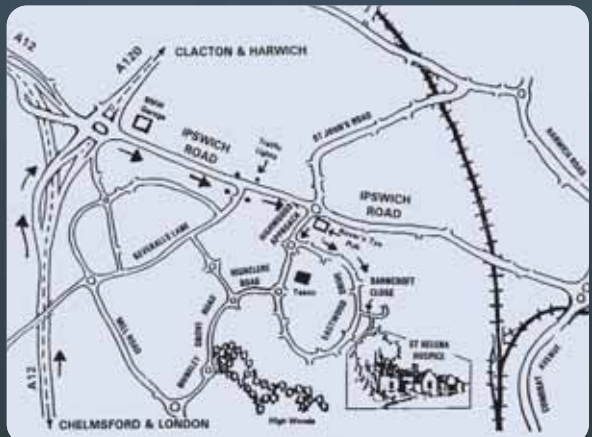
Take the A12 to Colchester. Then take the A1232 exit marked Colchester/Harwich. Keep in the left hand lane and slip off left to Colchester/Ardleigh. At the roundabout take the 3rd exit. Go straight on at the traffic lights. Take the 3rd exit (Rovers Tye Public House) at the next roundabout. There are signs for St Helena Hospice and Highwoods Shopping Centre. At the next roundabout take the 1st exit into Eastwood Drive and then take the 5th turning on the left into Barncroft Close. St Helena Hospice, including the Joan Tomkins Day Centre, the Inpatient Unit and the Education Centre are on the right.

By car from Clacton

Take the A120 to Colchester. Then take the A1232 exit. At the roundabout take the 1st exit and follow directions as above.

Public Transport

There are a number of regular bus services to St Helena Hospice or nearby Tesco Highwoods just five minutes walk away. For the most up to date information please consult Colchester bus station. The bus from North Station (rail services) takes approximately ten minutes.





Directions to: St Helena Hospice, Tendring Centre

When entering Clacton on the A133 follow the signs for the Sea Front.

You will eventually drive down Carnarvon Road, a wide road with the sea visible ahead.

At the end turn right on to Marine Parade.

Continue past Pier Avenue and take the next right turn into Agate Road.

Bear left at the end into West Avenue and the Hospice is directly ahead.

The Hospice's main car park is on the right, just past the building.



St Helena Hospice

your time...your hospice

St Helena Hospice

Myland Hall Inpatient Unit
Barncroft Close, Highwoods
Colchester CO4 9JU
t : 01206 845566
f : 01206 843294
e : request@sthelenahospice.org.uk

St Helena Hospice

Tendring Centre
Jackson Road, Clacton-on-Sea
CO15 1JP
t : 01255 221222
f : 01255 435409
e : request@sthelenatendring.org.uk

St Helena Hospice

Joan Tomkins Centre
Barncroft Close, Highwoods
Colchester CO4 9JU
t : 01206 848163
f : 01206 752245
e : request@sthelenahospice.org.uk

St Helena Hospice

Education Centre
Barncroft Close, Highwoods
Colchester CO4 9JU
t : 01206 851560
f : 01206 845969
e : education@sthelenahospice.org.uk

St Helena Hospice

Fundraising Office
95-97 Magdalen Street, Colchester
CO1 2LA
t : 01206 791740
f : 01206 793477
e : enquiries@sthelenahospice.org.uk



The images used throughout this guide are of the specially commissioned stained glass window that is situated in the newly modernised and refurbished Joan Tomkins Centre. Designed and created by local artist Surinder Warboys and paid for through our grant from the Department of Health, the piece was born from her time spent in the gardens at the Hospice, photographing and sketching the lily pond. The intention of the final design is to present the viewer with a reflection of the elemental and floral world around us. The filtered light and colour from the natural world outside shift as the day passes.

St Helena Hospice is a company Limited by guarantee.

Registered in England and Wales Number 01511841

Registered Charity Number 280919

Registered Office:
Myland Hall, Barncroft Close, Highwoods, Colchester. CO4 9JU

Colchester: Inpatient Unit, Joan Tomkins Centre, Education Centre.

Clacton-on-Sea: Tendring Centre.