

# Information for Patients and Visitors



Phyllis®  
Tuckwell  
Hospice Care  
...because every  
day is precious

...because every  
day is precious



**Holistic support for patients and families**  
Clinical - Practical - Emotional - Spiritual - Financial

# Welcome to Phyllis Tuckwell

**We are here to care for you, whether you are one of our patients, or a relative, friend or carer.**

We will help you through the difficult times, as well as sharing with you the times of hope and joy, supporting you to live well, and always treating you and your loved ones with compassion, dignity and respect. All of our team, from nursing staff to volunteers and support staff, are here for you and your loved ones.



**Our care is provided free of charge to our patients and their families and carers.**

However, as the NHS/Government usually only covers around 20% of our costs, the majority of our funds come from other people who care as passionately about our services as we do.

We are grateful that so many people in our community give their time and money to enable us to continue providing our care, and hope that you take comfort from their support.

We have to raise over £25,000 every single day to provide all our services. If you would like to support us in doing this, details can be found on page 12.

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## Introduction

This booklet has been written to give patients, families and carers an overview of the services offered by Phyllis Tuckwell.

Phyllis Tuckwell Hospice was founded by Sir Edward Tuckwell, whose wife Phyllis died of cancer.

Our vision is to provide easy access to compassionate supportive and end of life care for patients and families in a place of their choice.

Our mission is to care compassionately for adults living with an advanced or terminal illness, and those closest to them, so that they have the best possible quality of life and the patients' final days are peaceful.

The management of pain and other symptoms, and the provision of psychological, social and spiritual support, are paramount. We are committed to offering choice, and to identifying and supporting what is important to you, as well as addressing your needs.

## Referral to Phyllis Tuckwell

Patients, relatives or friends can make an initial enquiry about hospice care.

A healthcare professional will then need to make a formal referral to provide us with the clinical information needed. These referrals may be made by a doctor, nurse or other healthcare professional.



# Living Well

Our Living Well service is designed to help patients, and those closest to them, to manage the impact of their illness, cope with changes, improve their wellbeing and remain as independent as possible – so that they can get the most out of life.

We offer patients, and their families and carers, access to high quality, compassionate care in their homes and care homes, as well as at our Beacon Centre. The skills and expertise of our highly trained specialist palliative consultants and doctors, clinical nurse specialists, registered nurses, benefits & entitlements advisors, pastoral care team, therapists and counsellors gives them, and their family and carers, access to the vital support that's needed at this difficult time.



We work closely with patients' GPs, district nurses and other healthcare professionals involved to ensure that patients' needs are met. We provide support to manage symptoms, assist with advance care planning, provide physical and psychological care, and provide access to information and therapies tailored to each individual's needs.

Following an initial assessment, patients can access a range of services either through home visits or by attending the Beacon Centre.

Patients may attend the Beacon Centre as an outpatient for a variety of reasons:

- to be seen in one of our clinics
- to attend group sessions
- for the ongoing monitoring of their healthcare needs
- to enjoy and benefit from meeting others in a supported environment.





# Clinical Nurse Specialists (CNSs) and Community Doctors

**Our team of Community CNSs and doctors are experienced healthcare professionals who have undergone further palliative care training and have gained specialist qualifications.**

They advise on managing symptoms, and provide information to patients, relatives and carers. They visit patients in their own homes, in care homes or see them at the Beacon Centre. CNSs can also arrange referrals to other Phyllis Tuckwell services.

The team work closely with hospital consultants, with GPs and other community nurses.



The team provides a seven-day service 8am to 6pm and can be contacted Monday - Friday via 01252 729440.

At weekends or for urgent queries during evenings or overnight, call 01252 729400.

# Therapies

Our Therapy teams work across all areas of our service, seeing patients at home, as outpatients at the Beacon Centre and on our temporary In-Patient Unit at Kings Lodge.

## Occupational Therapy

Being able to continue with everyday activities and occupations is important to a person's wellbeing.

Our occupational therapists help patients solve the difficulties they may be experiencing with:

- looking after themselves,
- looking after their home and family,
- continuing their work, leisure and social activities,
- adapting to changes in their abilities and lifestyle, including helping them to make plans for discharge home from the Hospice.

This may be by using a new piece of equipment, developing a coping strategy, or deciding to get some practical help.



## Physiotherapy

This aims to improve patients' quality of life and help them to remain as independent as possible through all stages of their illness.

Types of treatment may include:

- exercise programmes,
- provision of walking aids and other equipment,
- assistance with the relief of various symptoms e.g. pain, breathlessness or muscle weakness,
- advice on adapting to changing circumstances, managing activities, and manual handling issues for patients and carers.

## Complementary Therapy

Complementary Therapies are offered to our patients for wellbeing, relaxation and the management of distressing symptoms.

Our complementary therapists offer many different types of treatments including aromatherapy, reflexology, Indian head massage and reiki.

## Patient and Family Advice

**Our Patient and Family Support team offers emotional and practical support to patients and their carers.**

They can help to ensure a smooth discharge for patients who are able to go home after a stay on our IPU, and facilitate care home placements for those who require them. They can apply for funding for support where necessary, and liaise closely with Social Services and the NHS to ensure that patients receive the necessary practical help needed.

## Emotional Support

**Coping with an advanced or terminal illness is difficult not only for patients but also for their families and friends. We support patients, families and carers by offering formal counselling or an informal 'sit and chat' service.**

We continue to support families and friends after the death of their loved one through individual counselling, coffee mornings, and services in remembrance of those who have died.

**We recognise that children and grandchildren (under 18s) may need specialised support, and our children & families counsellors and child psychologists can help with this.** There is also a bereavement group for children: 'Little Rays' for 5-12 year olds.

## Welfare

**Our patient & family advisors can help guide and advise patients on the support they may be eligible to receive, and can provide information on completing forms and/or signpost to relevant agencies.**

This can include claiming benefits and applying for disabled car badges. They can also advise patients and their carers about other services, such as making a Will, arranging travel insurance and applying for grants.







## Pastoral Care

The Pastoral Care team are responsible for the spiritual care of our patients, families and carers, irrespective of their faith and inclusive of those who have no faith.

Our Pastoral Care team can give Holy Communion at any time - by a patient's bed or at the Beacon Centre, where patients may come to attend our Living Well sessions.

## Hospice Care at Home

**Our Hospice Care at Home team support very ill patients who would prefer to spend their last days, and to die, in the comfort and familiarity of their own home.**

They provide nursing care to help patients and their families cope with the final few weeks and days of life. They co-ordinate with district nurses, GPs, Social Services and other agencies and care providers involved.



## Home Support

**Our small Home Support service provides volunteers to help patients and families at home.** Our team of volunteers can help patients and their families in many practical ways, such as:

- shopping or ironing,
- taking patients on outings,
- accompanying patients on hospital visits,
- allowing carers a few hours off for a well-earned break.

Often the greatest help we can give is just to sit and listen.



# In-Patient Unit (IPU)

Our IPU, which is temporarily situated at Kings Lodge in Camberley, provides specialist palliative care through our team of specialist consultants, doctors, nurses and health care assistants.

## Notes for inpatients and their visitors:

### Things to bring

Patients are welcome to bring with them small, familiar items to make them feel more at home, such as their own pillows, photographs or pictures, books or a radio or CD player (electrical items need to be checked by our maintenance engineer before use).

A television with earphones is available at each bed.

Patients also need to bring toiletries, nightclothes and daywear (if appropriate), slippers etc, but are requested not to bring towels.

### Valuables

We request that patients do not bring valuable items or large sums of money as we cannot take responsibility for the loss or damage to these whilst on the premises.

### Medications

When patients are admitted to the IPU we request that they bring with them any medications that they are currently taking or have recently taken. These should be handed to the Nursing staff.

### Use of IT facilities

Access to the Internet via the Hospice wireless network is provided.

# Visiting Times

Visiting is 24 hours per day.



# Healthcare Professional Visitors

General practitioners, community nurses and hospital consultants are welcome to visit their patients at Kings Lodge.

Nurses undergoing their training or doing post basic training, and other healthcare professionals, may work in Kings Lodge for short periods. This allows them to gain experience of palliative care in a palliative care setting.

# Fundraising/Donations

All of our services are provided free of charge. Part of the cost of running our services is covered by an annual grant from the NHS/Government, however this contribution usually only amounts to around 20% of our total running costs. Phyllis Tuckwell is a registered charity and relies greatly on the support and generosity of our community. Our registered charity number is 264501.

We are very grateful for any donations to help fund our hospice care. We respectfully ask for financial donations rather than gift items, such as garden furniture, pictures, trees, etc.



If you would like to make a donation, please speak to a staff member. If you would like to speak to a member of the Fundraising team, then please ask a member of staff, call 01252 729446, or email [support@pth.org.uk](mailto:support@pth.org.uk).

# Volunteers

We are fortunate to have a large and active team of volunteers, and without their help many of the services that we provide would not be possible.

Our volunteers help in many different ways including welcoming visitors at reception, helping at our Living Well sessions and on the IPU, transporting patients and helping in our shops.

We provide training and ongoing support to all our volunteers.



# Health & Safety

You are required to take reasonable care of your own health & safety and that of other persons who may be affected by your acts or omissions. If you have any concerns about health & safety, please let us know.





# Data Protection

## How we use your personal information

In order to provide you with the best possible care, we hold your personal details electronically and on paper.

We take every care to safeguard your confidential information and it will be kept in accordance with the Data Protection Act 2018 and General Data Protection Regulation (GDPR) requirements.

Information relating to your diagnosis, care and treatment will be shared across the Phyllis Tuckwell multi-disciplinary team to ensure all the healthcare professionals involved can provide good care.

## Sharing Information

Sometimes your clinical information will need to be shared with other healthcare professionals such as your GP, community nurses, hospital teams and Social Services, in order that they can provide the care you need. We operate an “implied consent” model. We only share your information with other healthcare professionals when we need to, and we work on the basis that most patients are happy with this. However, you can request us not to share your information with other professionals, but this may affect their ability to care for you properly.

We are also able to view your healthcare records held by your GP and community nurses.

When you are referred to Phyllis Tuckwell, your GP or other healthcare professional should inform you that your healthcare records can be viewed by our clinical staff. Referral and acceptance of care from Phyllis Tuckwell implies that you are happy for us to view these records but, although we would strongly advise against it, you can request that we do not read your GP records.

**If you would like any further information about clinicians sharing and viewing your healthcare information, please contact our medical director at [cate.seton-jones@pth.org.uk](mailto:cate.seton-jones@pth.org.uk)**

You are entitled to state if you do not wish any of your details to be discussed with your next-of-kin, other family members, or carers.

### We may also use your information in the following ways:

- In order to monitor and improve our standards of care we undertake regular audits of patient care. Staff outside of the care team may be involved in this process and they will also keep patient information confidential.
- We are regulated by the Care Quality Commission and we are required by law to submit patients' contact details on request, unless patients have requested otherwise.
- We provide fully anonymised grouped information about how patients use our services, for national monitoring and evaluations.
- We may use anonymous data, e.g. number of patients, percentage of patients, to apply to Trusts to gain additional funding.

- We may use very specific personal information including images/story/quotes, but this will always be with the person's signed consent.

Our staff will not divulge any information relating to patients and their families to the media, or anyone else, without consent.

- In most circumstances your health records will be retained by Phyllis Tuckwell for 10 years before they are confidentially destroyed. In special situations some healthcare records will be retained for 30 years.

In line with the Access to Health Records Act 1990, you have a legal right to access your own records.

Should you require more information on how we use or protect your information, please ask to speak to the medical director or the director of patient services.

If you would like to complain about how Phyllis Tuckwell has handled your personal information, please contact the medical director of Phyllis Tuckwell or the Information Commissioner's Office (ICO helpline - **0303 123 1113**).

## Information about your Medicines

**Generally medicines prescribed by your Doctor or bought over the counter from a pharmacist are licensed for use by the Medicines and Healthcare products Regulatory Agency (MHRA).**

The licence (or marketing authorisation) specifies the conditions and patient groups for which the medicine should be used, and how it should be given.

Patient Information Leaflets supplied with medicines reflect the licensed uses. When a medicine is used beyond its licence, the information in the Patient Information Leaflet may not be relevant to your circumstances.

**In palliative care, medicines are commonly used for conditions or in ways that are not specified on the licence.** Your doctor will use medicines beyond the licence only when there is research and experience to back up such use.

### **Can I drive when I am taking medicines?**

It is illegal in England and Wales to drive with prescription or over-the-counter medicines in your body if

it impairs your driving, or you have over the specified limits of these drugs in your blood which have not been prescribed for you.

These drugs include medicines such as methadone, morphine, oxycodone, fentanyl, codeine or tramadol, and also drugs like diazepam, clonazepam, lorazepam and temazepam. Some of these medications are commonly used in palliative care, so you may be taking one or more of them.

You can drive after taking these drugs if:

- you have been prescribed them and followed advice on how to take them by a healthcare professional
- they are not causing you to be unfit to drive.

We advise that you do not drive while taking your medicine, until you know how it affects you. Do not drive if you feel drowsy, dizzy, unable to concentrate or make decisions, or if you have blurred or double vision.

We would also advise that you keep a copy of your prescription in the vehicle with you.

To find out if your medicine may impair your driving, and therefore whether you can drive, read the warning label on the box or bottle, and the patient information leaflet supplied with the medicine, or talk to your doctor, pharmacist or healthcare professional.

### **What should I do with unwanted medicines?**

If you have medication at home which you are no longer prescribed or which has passed its expiry date, you should take it to your local pharmacy where it will be destroyed.

Further information about your medicines can be found in the relevant patient information leaflets supplied with the medicines.

### **Further advice**

- For advice you can call the Pharmacy medicines helpline at Frimley Park Hospital on 0300 613 4744 (weekdays 9am-5.15pm).
- Alternatively ask your pharmacist at your local chemist.
- Your Phyllis Tuckwell doctor or registered nurse may be able to help with any other questions you may have.

## **Resuscitation**

It is very rare for the heart or lungs to stop unexpectedly. Experience tells us that in people with conditions such as advanced cancer, motor neurone disease or end stage heart or lung conditions, cardiopulmonary resuscitation (CPR) is rarely successful.

**At Phyllis Tuckwell, each patient is assessed individually by a doctor or clinical nurse specialist, and a decision is made as to whether CPR may be beneficial.**

For the majority of our patients, CPR will not successfully restart the patient's heart or breathing. The decision about CPR will not affect any other treatment that you are given. If your medical condition is such that the doctor thinks you might respond to CPR, the doctor will discuss this with you.

## **Smoke-Free**

**Patients and their relatives may only smoke or vape in the designated outdoor smoking area in the garden.**

Please dispose of all cigarette ends in the receptacle provided and not in the flowerbeds or on the lawn.

## Contacting Phyllis Tuckwell

Patients who are living at home may sometimes need to contact us for advice and support. They, and their families and carers, may do this at any time, day or night, including weekends and Bank Holidays.

The best way to do this is to phone Advice and Referral on 01252 729440 (Monday to Sunday, 8am - 6pm) and ask for the person you would like to speak to.

Outside of normal working hours, calls will be put through to the nursing staff on the IPU and they will be able to help you.

## Regulating Body

We are regulated by the Care Quality Commission and are required to submit a rigorous self-assessment of our services.

Copies of our Quality Account and Inspection reports are available on request.

Any person wishing to make a complaint should follow the procedure laid out in the leaflet entitled 'Have your Say'. However, if a person feels unable to do this they are encouraged to contact the Commission directly at the following address:

**Care Quality Commission,  
2 Redman Place, Stratford,  
London E20 1JQ.**

**Telephone: 03000 616161**

**Email: [enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk)**

## Complaints

We want to know when things go wrong as well as when they go right.

It is important that we learn from the experiences of our patients and their relatives and carers so we can improve our services for others.

**If you have a complaint please tell someone as soon as possible, or ask a friend or relative to do so on your behalf.**

We operate a complaints procedure and there is a complaints/suggestion box with cards at main reception and in the Coffee Shop.



## Where to Find Us

**Kings Lodge**, 122 Kings Ride, Camberley, Surrey GU15 4LZ

### By Rail

Trains from London Waterloo run regularly Monday to Sunday.

Kings Lodge is situated off of Kings Ride, a 20-minute walk from the station.

### By Car

There is a car park at Kings Lodge and roadside parking is available on surrounding roads.

**The Beacon Centre**, Gill Avenue, Guildford, Surrey GU2 7WW

### By Rail

Waterloo to Guildford on the Portsmouth line. Taxi journey is 10 minutes from Guildford Station. Buses run to the Royal Surrey County Hospital (RSCH), the Beacon Centre is situated in its grounds.

### By Car

From London:

Take the A3 south towards Portsmouth. At Guildford, take the exit marked “Cathedral, University, Hospitals and Holiday Inn”. Take the 3<sup>rd</sup> exit from the roundabout and go straight over the next roundabout. Cross the traffic light junction and go up Gill Avenue. The Beacon Centre can be found on the site of the RSCH and access to the Beacon Centre’s car park is through the RSCH staff car park, which is well marked to the right.

From A3 south:

Take exit marked “Holiday Inn”. From the roundabout, take the first main exit (do not turn directly left). Go straight over the next roundabout and then straight ahead over the traffic light junction and up Gill Avenue. The Beacon Centre is on the site of the RSCH with access as above.



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**This booklet is written specifically for patients, carers and families.**

Should you wish to make any comments or suggestions relating to the content or layout of this booklet, please ask to see our director of patient services or, if you prefer, put your views in writing and send them to her at the address below. **All comments and suggestions are appreciated.**

**Main telephone numbers:**

**Advice and Referral Team  
01252 729440**

**Main reception  
01252 729400**

***Large print version  
available on request.***

**Correspondance address:**

Waverley Lane, Farnham,  
Surrey, GU9 8BL  
Tel: 01252 729400  
**[www.pth.org.uk](http://www.pth.org.uk)**

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