



Priscilla Bacon Lodge: Specialist Palliative Care Inpatient Unit

A guide for inpatients and carers



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Welcome to the Priscilla Bacon Centre for Specialist Palliative Care

The Priscilla Bacon Centre for Specialist Palliative Care provides care to people from across Norfolk. Our specialist palliative care team become involved if your needs are more complex.

It aims to offer flexible and responsive services that give people access to a range of high quality palliative care, whenever and wherever they are needed.

It does this through three ways of delivering its services; these are:

- **A specialist inpatient unit - Priscilla Bacon Lodge**
- A specialist day unit – The Rowan Day Centre
- The Community Specialist Palliative Care Team, which often works within people's own homes or places of residence across the county

Services provided include:

- Medical outpatients and a range of treatment clinics
- Advice on pain control and management of symptoms
- Breathlessness support service
- Occupational therapy and physiotherapy
- Psychological support clinics
- Emotional support for patients, family, friends and carers
- Complementary therapies

- Information on conditions, their treatment and any additional support available
- Spiritual support
- Palliative Care Social Work Team

The centre's multidisciplinary teams work closely together and with GPs and community nurses, as well as any other health or social care professionals involved in a patient's care.

In this booklet we have tried to include all of the information you will need to help you, your family or carers. If you have any further questions, please do not hesitate to talk to a member of the team.

What is specialist palliative care?

Specialist palliative care is the treatment and care offered to people who have life-limiting illnesses, such as cancer, respiratory disease, heart failure and advanced neurological diseases.

The care offered focuses on the need of the 'whole person', as well as their family, carers and friends. It is not just about managing pain and physical symptoms, but includes support for emotional, social and spiritual needs, care in bereavement, and even support in dealing with the financial effects of having a life-limiting illness.



Priscilla Bacon Lodge

Priscilla Bacon Lodge (or PBL for short) is a specialist inpatient service for people who have complex palliative care needs including physical, emotional, social and / or spiritual needs.

It is a short-stay unit which has been providing palliative care to local people for more than 25 years.

A patient is referred to PBL when their needs require support from a specialist multi-disciplinary palliative care team, and when this cannot be adequately provided in a person's current place of care, or within their own home.

For example, patients can be admitted for inpatient care if they require:

- Complex symptom management
- Rehabilitation
- Help with complex psycho-social problems
- End of life care

Patients are cared for in spacious bays (maximum of four beds) or single rooms depending on their level of needs.

“ Thank you to all the staff for being beautiful people and for having big hearts. You are amazing, keep up the good work... ”

What can I expect while I'm at PBL?

Making decisions with you

The healthcare team at Priscilla Bacon Lodge (PBL) will regularly discuss with you your care plans and treatment options. These will only be shared with your family, carer or an elected close friend, with your permission.

Any decision you make about your treatment will be respected by all members of the healthcare team.

Preferred Priorities for Care

Another primary aim of the team is to, wherever possible, meet any patient's Preferred Priorities for Care for when they near the end of their life.

Discussing and talking about their choices can help a patient prepare for the future, and gives them the opportunity to think about the care they would like to receive and where they might like to receive it.

Our care and treatment

Our care is best described as 'active supportive care' and the management of pain and other symptoms is of paramount importance.

All members of the multidisciplinary team have specialist skills and training to help alleviate a wide range of complex and distressing problems.

If you experience pain, feel breathless, sick or feel anxious, or experience any other symptoms,

please inform a member of staff as soon as possible.

Whenever it is medically appropriate, we may offer treatments such as blood transfusions, intravenous fluids, antibiotics and investigations, including blood tests, scans and x-rays.

Scans and x-rays are performed at the Norfolk and Norwich University Hospital and, if these are necessary, we may ask for a friend or relative to accompany you.

PBL has limited resuscitation facilities and in the case of sudden unexpected collapse, we offer basic life support only. Your doctor may discuss the issue of resuscitation with you. The outcome of this conversation will be documented in your notes.

Patients referred to PBL are discussed regularly at the multidisciplinary team meetings. We also work closely with your GP and / or community nurse.





Administration of medicines

The administration of medicines takes place regularly during the day.

These drug rounds can be long and complicated. The nurses would therefore appreciate not being interrupted when medicines are being given to you or another patient.

If you have any questions regarding medication, please feel free to ask these when the medicine round is completed.

Other members of the team are available to help you during these times. Please ring your bell if you need a nurse or some assistance.

If you feel you need medication at any other time, please do not hesitate to ask your nurse.

Rest period

Our patients have said that having a regular rest period is important to them. Therefore we offer all of our patients a rest period **between 1pm and 3pm**. This quiet time will provide you with an opportunity to rest as well as have some personal time.

There may be times when your doctor may wish to see you during rest time. Should there be a reason why you do not wish to be disturbed at this time, please bring this to the attention of one of the nurses looking after you.

If you do not want to participate in the rest period, please tell your nurse and an alternative place to spend this time will be offered to you.

Any visiting during this time should take place outside of the immediate ward area.

Who will provide my care?

Your care will be provided by a team of health and social care professionals who have the experience, skills and knowledge to offer you support throughout your stay at PBL.

You may need support from some of these professionals, or all of them.

The team includes:

- Consultant-led medical team
- Nursing team
- Physiotherapists
- Occupational therapists
- Healthcare assistants
- Psychological Service
- Social worker
- Complementary therapists
- Chaplaincy team
- Volunteers

Doctors

The medical team at the Priscilla Bacon Centre work closely with other colleagues to review patients' symptoms and help improve these. The team reviews patients seven days a week, and are available 24/7 in emergencies.

Our consultants are specialists in palliative medicine and we also have a consultant in pain management who works with us to support patients who need pain management procedures, such as nerve blocks.

The medical team is happy to be contacted at any time on 01603 255729.

If you would like family members to be present when your consultant does their ward rounds, this can easily be arranged; ask your nursing team or call 01603 255729.

Nursing team

Nurses experienced in specialist palliative care provide 24/7 skilled care. They work closely with the multidisciplinary team to provide high quality patient centred care which is focused on achieving goals.

Physiotherapists

Physiotherapists work with patients to help improve their movement and any physical problems they may develop as a result of their life-limiting condition. They also help patients avoid any complications which can be caused by limited movement or posture.

Working with a patient during their stay, and often after they are discharged, they will create an individual programme of physical therapy to help with weakness, balance and muscle spasm, for example.

Promoting wellbeing and independence, the team can also help with: symptom control, including breathlessness and pain management; sourcing equipment; advising families and carers on moving or supporting a patient.

Occupational therapists

Occupational therapists help people achieve as much independence as possible in their everyday personal and domestic activities.

After assessing each person's physical, social and environmental needs, with involvement from family, carers and friends, occupational therapists can offer rehabilitative plans or treatments, including outpatient and home visits.

They provide help and advice on things including:

- Adjusting to changes in levels of energy, physical ability, and appearance
- Relaxation, motivation and self-esteem
- Assessment and prescription of support aids

Healthcare assistants

Healthcare assistants support the work of the qualified nursing and therapy professionals. They help patients with personal care and activities of daily living.

Psychological Service

While someone is a patient in PBL, they and any member of their family can be seen by our Psychological Service.

The Psychological Service provides counselling and other forms of psychological support to help people deal with the emotions and changes they face during illness and become more confident about coping.

Social worker

Social workers are an integral part of the PBL team. They advise and support patients, and their families and carers, on how to access appropriate services and social care on discharge.

They can assist in setting up support plans for patients and establish eligibility for funding schemes, such as NHS Continuing Healthcare or local authority personal budgets. They will also advise patients who are not eligible.

With a patient's agreement, they can liaise with and refer to other organisations for things including benefits advice, assistance with application forms, or help with managing fi

The social worker can also support patients and their families with things including: legal issues, including powers of attorney; end of life decisions; bereavement worries; and funeral arrangements.

Complementary therapists

Complementary therapists provide a range of therapies, including massage and reflexology, to compliment the other treatments you are receiving.

Chaplaincy Service

The hospital chaplain can visit you at your request regardless of your faith. Alternatively, we can arrange for you to be seen by someone from your own faith.

Volunteers

We are well supported by a large team of skilled and committed volunteers who provide invaluable support to many parts of the service.

Further support

Further assistance is offered to patients by our support, housekeeping and administration staff based within the unit, and by our team of dedicated volunteers.



What should I bring with me?

Please bring:

- All medications you are currently taking
- Toiletries, including shaving equipment, denture cleaner, if used, and tissues
- Nightwear and underwear, including a dressing gown and slippers
- A selection of comfortable clothes, as we encourage those that can to dress
- Any continence products you may use, such as pads
- Any walking or hearing aids
- Small personal items, eg, photographs
- Fruit cordial / fizzy drinks, etc

Storage at PBL is limited. To help us maintain a clean and safe environment, please send all unnecessary items home, including bags and suitcases.

Mobile phones

You are more than welcome to keep your mobile phone with you during your stay in the unit.

But to minimise disruption to other patients we ask you:

- Not to take your mobile phone into your therapy sessions
- Respect other ward users when using your phone
- Not to use a mobile phone after 10pm

Electricals

For safety reasons all personal electrical items must be checked by the site electrician before they are allowed to be used in the unit – please ask staff for advice on this.

Personal property and valuables

We regret that the unit cannot accept liability for money or valuables and you are therefore advised to leave these at home for safe keeping. The only money you are likely to require will be for the Trolley Shop, etc.

If leaving your valuables at home is not an option, the nurse in charge can place them within the hospital safe and give you a receipt. On discharge you will need to ask the nurse in charge to arrange for the items to be returned.

If cash was handed in it is likely to be returned to you as a cheque for the same amount as large amounts of money are not kept on site for security reasons.

What are the arrangements for visitors?

Visitors

Family, children and friends are welcome to visit.

We ask that you, your family and visitors give consideration to the privacy of other patients and:

- Show courtesy and respect to other patients, family members and all staff
- Work with staff to get the most from the patient's care
- Communicate appropriately with the relevant member of the team. Don't hesitate to ask questions
- Keep pets and children under control at all times
- Park in appropriate bays and do not block ramps or driveways

Visiting times

Visitors are welcome; however, we prefer them to come between **10.30am - 12 noon** and **3pm - 8pm**. This gives us time to meet personal care needs, and for you and other patients to benefit from suitable rest periods.

We understand that there may be a need for flexibility – please speak to a member of the nursing team.

We ask that you limit the number of visitors at your bedside to two at a time, and visitors may be asked to leave while nursing staff provide care.

To help prevent the spread of infection, visitors are asked to use the alcohol hand rub on arrival and when leaving.

Security

For security purposes, the unit is always locked after 9pm.

If the unit is locked there is a doorbell to request access. On occasions, due to the busy nature of the unit, visitors may have to wait a short while to be let in, but staff will respond as soon as possible.

Pets

Pets may visit at the discretion of the nurse in charge. Please discuss this with your healthcare team. An information leaflet is also available.



Visitors staying overnight

If your condition changes and you become less well, it may be possible for a close relative or close friend to stay overnight.

This will be discussed with you and any decision made will be reviewed on a day-to-day basis.

If possible, this decision should be made before 8pm so that appropriate arrangements can be made for their stay.

As space is limited, we may only be able to offer an overnight stay to two visitors per patient, although this is flexible and dependent on the situation and the patient's condition at the time.

After 9pm, a member of the night team will show your visitor where they may stay. They will be offered a light breakfast at 7am.

Washing facilities and toilets for visitors are located opposite the Main Reception of PBL. Visitors should not use the patients' toilets.

We may suggest that your overnight visitors return home to freshen up. Another relative may be able to stay at your bedside during this time. If this is difficult, please speak to a member of staff as they may be able to help.



Flowers and gifts

You may appreciate flowers and gifts but please bear in mind that we have limited space.

If you need any further guidance, please speak to the housekeeper who will be happy to advise you.



What are the arrangements for mealtimes?

Protected mealtimes

We run a protected mealtime system, which we ask visitors not to disturb, to help provide the ideal environment for you to eat your meals with minimal distractions.

We welcome visitors who are there to assist relatives and friends with eating their meals.

- Breakfast - 7.30am
- Lunch - 12.30pm
- Supper - 6.15pm

A daily choice of meals and hot drinks are provided throughout the day.

Please discuss any special dietary needs that you may have with the nursing staff or housekeeper. Our aim is to ensure all dietary needs are catered for.

Nutritional advice is also available from the nursing team or arrangements can be made for you to talk to the dietician.

Advice around foodstuffs

The unit cannot take responsibility for the safe handling of food we have not provided and, due to food hygiene standards, we advise against family / friends bringing food in for you.

If, however, you feel this is the only option to ensure your dietary needs or preferences, then please discuss with your care team.

Foods which are not 'high risk' (please ask for more information) can be stored in the ward fridge for a short time providing it is in an appropriate container, with a name and date on.

Please discuss this with the nursing team who can provide labels if required. Items left in the fridge unlabelled or with a shelf life of less than 24 hours will be removed and disposed of.

What facilities are available?

Patient and visitors' lounge

At PBL we have a patient and visitors' lounge, with tea and coffee facilities available for a donation. This can be found immediately in front of you, as you enter the main reception area.

Here you will also find a small children's play area and toys.

There is also a snack vending machine in the main reception area, and local shops and cafés close to the unit. A member of staff will be happy to advise your visitors how to find these.

The Garden Room and PBL Garden

The Garden Room adjoins the lounge, and is a comfortable and restful area in which people can enjoy visits or socialise with other patients, as well as watch television, read a book, listen to music, etc.

It opens onto the peaceful garden which patients and visitors are welcome to enjoy.

Information area

There is an information area for patients and carers within the Garden Room. This includes access to a laptop and WiFi.

Trolley Shop

The Trolley Shop visits the unit weekly, selling a small range of toiletries and confectionery.

Refreshments

Our volunteers bring a drinks trolley around the ward regularly offering a range of beverages.

Laundry

Priscilla Bacon Lodge does not have a personal laundry service. Please ask your family or friends to collect personal clothing regularly.

Hairdresser

If you need a hairdresser, please discuss with the ward staff who will explain how to access this service.

Newspapers

We have a selection of newspapers delivered which are kept in the coffee lounge for use by both patients and relatives.

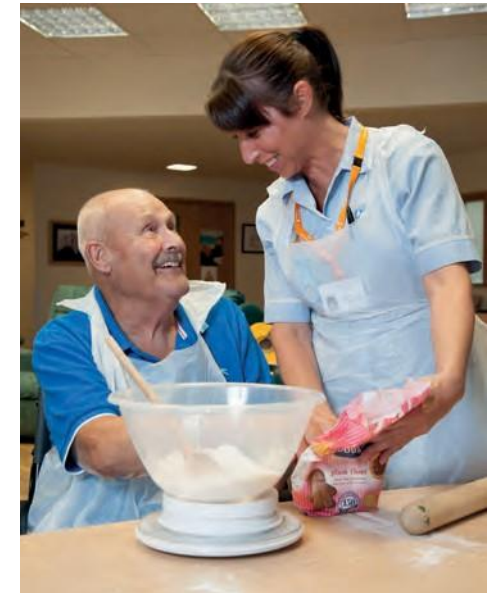
Audio visual entertainment

At your bedside you will have access to a personal TV and WiFi. It is supplied with headphones to minimise noise disturbance to other patients. CD players and a selection of CDs are available to borrow.

The Rowan Day Centre

During your stay you may benefit from the activity sessions or complementary therapies provided as part of our service by fully qualified practitioners.

These take place at your bedside or in The Rowan Day Centre, which is linked by corridor to Priscilla Bacon Lodge. Ask a member of staff for the information booklet on these therapies.



Chaplaincy

Sunday services are held in the chapel here at Priscilla Bacon Lodge, at 11.30am.

If you would like help to attend the Sunday service, please discuss this with your healthcare team. Your family and friends are also very welcome to attend.

A more detailed leaflet on the Chaplaincy Service is available on request.

How do I keep family and friends updated?

We encourage your family, carers and friends to be involved with you during your stay in Priscilla Bacon Lodge (PBL).

With your permission (the patient's), staff at PBL are happy to discuss with your next of kin, or someone you have chosen, what is happening during your stay, and plans for your care.

The team at PBL can meet with you, and any close family or carers, to discuss your care plans, plans for returning home, or for your transfer to a long-stay facility after your time at PBL. Patients are fully supported through this discharge process.

More information on sharing information and the discharge process is provided on pages 12 and 17 of this booklet.

With your consent people can be updated by phone, but please note, only limited information can be given over the phone due to confidentiality.

To ensure as much time as possible is spent caring for our patients, we would be grateful if one family member or chosen person phones the ward and then passes the information on to other friends and relatives.

We would appreciate it if calls to the unit were made **after 9am**, but please be assured that if you need your family, or there is a change in your condition, we will notify them immediately.

You are also welcome to keep your mobile phone with you during your stay in the unit, and more information on this can be found on page 10. A laptop and WiFi is available for your use.

Useful telephone numbers

- To talk directly to a patient: 01603 255713
- To enquire about a patient: 01603 255724
- To discuss admissions and discharge: 01603 255730
- To talk to the medical team: 01603 255729
- Priscilla Bacon Lodge Ward Manager's office: 01603 255723
- Priscilla Bacon Centre's Main Reception: 01603 255720

Keeping in touch

We have a mobile patient phone for incoming calls so that your family and friends can contact you at your bedside.

There is a daily postal delivery and collection. Please note that we cannot provide stamps



What happens when I am discharged?

Priscilla Bacon Lodge has an Admission and Discharge Coordinator. They work closely with patients and their families, as well as with social workers and the continuing care team.

This is to ensure that everyone moving on from the inpatient unit is fully supported during the transfer of their care, and that the services involved are well coordinated.

Medication

When you are discharged you will be given a minimum of two weeks' supply of your medication. After this, you will need to get a prescription from your own GP.

Community services

Your GP will be told that you have been discharged and will be given details about what has happened while you have been in PBL.

Arrangements may be made for a community nurse to visit you at home, or you may be asked to see your practice nurse at your GP surgery or health centre.



Get involved in our service

We encourage our patients, their families and carers to be involved in the services we provide through the Priscilla Bacon Centre. If you would like to become more involved, please ask your Specialist Palliative Care Key Worker.

Become a member of our Trust

You can have your say on the future of local NHS health and care by becoming a member of our NHS trust – Norfolk Community Health and Care (NCH&C).

As a member you will join thousands of other local people who are already members and who help to influence the successful future of our trust and NHS care in Norfolk.

Simply visit www.norfolkcommunityhealthandcare.nhs.uk and click 'Join now' or ask a member of staff for a membership form.

Charitable donations

If you would like to make a donation to our charitable funds, please ask a member of staff for an information leaflet or visit the Get Involved section on our website, where you will find all the information you need.

www.norfolkcommunityhealthandcare.nhs.uk/Get-involved/

Volunteering

A wide range of volunteering opportunities are available across our health trust, and you can discuss these by contacting our Volunteer Coordinator on 01603 255719. You can also visit the Get Involved section on our website, where you can read about the rewarding experiences of our many volunteers and how their valuable support benefits our patients.



Further information and advice

In this booklet, we have tried to include all of the information you will need to help you, your family or carers. If you have any further questions, please do not hesitate to ask a member of your healthcare team.

There are a range of additional advice leaflets available, or you can log on to our trust's website at: www.norfolkcommunityhealthandcare.nhs.uk

The following agencies may also be of interest to you:

Citizens Advice Bureau (CAB)

Provides confidential and free advice and information

www.adviceguide.org.uk

Equal Lives

A comprehensive advice service that covers all Department for Work and Pensions benefits relating to illness and disability

Tel: 01508 491 570

www.equallives.org.uk

Dying Matters

Provides confidential and free advice and information

www.dyingmatters.org

Macmillan Cancer Support

Provides wide range of information for cancer patients and their families

www.macmillan.org.uk

Your experience of our care



As part of our aim to continually improve the quality of our services, we need to know what you think about the care we have provided. We want to hear any comments you may have so that we can keep getting better, together.

If you do have concerns about any aspect of your own, or your relative's care during your time at the unit we would urge you to **speak to a member of staff as soon as possible to help us put things right straight away.**

We also love to receive your positive feedback and compliments as these let us know we are doing our job correctly – letters and cards can be handed in at the unit.

Comments, compliments and complaints

A leaflet on how to formally lodge your comments, compliments and complaints is available from a member of staff or you can log on to our website at: **www.norfolkcommunityhealthandcare.nhs.uk**

Patient Advice and Liaison Service (PALS)

NCH&C PALS offers support and advice for patients and carers and can help to answer your queries / comments on:

Freephone (landlines only):

0800 088 4449

Email: pals@nchc.nhs.uk

Have your say!

We encourage you and your family to be involved in our service. You can give us feedback about the care you have received and help us to improve our services by completing a patient satisfaction survey. You can also give us your opinion about future service development by attending meetings.



Contact information

The Priscilla Bacon Centre for Specialist Palliative Care Services, Colman Hospital, Unthank Road, Norwich, NR2 2PJ

Tel: 01603 255724

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If you would like this publication in large print, Braille, alternative format or in a different language, please contact us on 01603 697492 and we will do our best to help.