

Student Handbook

Care Directorate



'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

WHO, 2011

"Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement." ACT/RCPCH, UK 2003



CONTENTS PAGE

• Strategy at a glance	4
• Our Values	5
• Strategy Summary	6
• A history of hospice palliative care services	8
• A history of children's hospice services in the UK	10
• A history of Keech Hospice Care	10
• What is Palliative Care?	13
• What is Children's Palliative Care?	13
• Link nurses, tutors and mentors	14
• Learning Opportunities	15
• Library Services	16
• Useful websites and further reading	
• General Information	21
• Care Directorate	22
○ Adult In-Patient Unit (AIPU)	22
○ My Care Co-ordination Team (MCCT)	24
○ Keech Palliative Care Centre (KPCC)	25
○ Independence and Well-being Service	27
○ Rare Neurological Conditions Service	28
○ Medical Team	29
○ Clinical Education Team	30
○ Children's Services	30
○ Supportive Care Team	34
○ Social Work (Children's Services)	37
○ Social Work (Adult Services)	38

Strategy at a glance

2018-2023



Vision

Making the difference
when it matters the most

Mission

To lead the way in providing excellent care,
supporting children and adults with life-limiting
conditions and those affected by death and dying,
helping them to live well and make every day count.

Strategic enablers

- To communicate effectively.
- To maximise the use of data.
- Utilise our resources well, maximise digital technology and due consideration to sustainability maximising impact.
- To listen, learn and act.

Strategic themes

- To deliver excellent care and support.
- To educate, innovate and research.
- To be well funded.
- To attract, retain and engage our people, valuing difference.
- To be well governed and well led.

Values



We deliver better
outcomes by
working together.



We take care of
each other.



We can be trusted
and are respected
for our professionalism.



We are
committed
and innovative.

Our Values



We deliver better outcomes by working together.

I value the contribution of my colleagues wherever they work or volunteer.

I look for ways to be more inclusive and welcoming of all.

I seek opportunities to work with others.

I readily share my knowledge and expertise.



We take care of each other.

I think about how my actions and words impact on those around me.

I listen to and value the contribution of others.

I act with compassion and kindness at all times.

I offer and receive feedback so that we can grow and develop together.



We can be trusted and are respected for our professionalism.

I can be trusted with your information and your care.

I can be relied upon to use your donation or gift wisely.

I have integrity and am accountable for my decisions and actions.

I act in a way that is fair and transparent and clear for all to understand.



We are committed and innovative.

I respect our resources and use them carefully.

I approach change with an open mind.

I look for ways to increase productivity and improve quality.

I am dedicated to what I do because the work of Keech inspires me.

Our Values underpin everything we do and we demonstrate them in the way we behave towards each other, our patients, their families and carers, our customers, supporters and our partners.

Strategy summary

2018-2023



Strategic themes

To deliver excellent care and support

- Support choice and co-ordination of services.
- Provide expert, person-centred, responsive and quality care.
- Ensure equal access for all.
- Develop community resilience at end of life and beyond.

To be well funded

- Work collaboratively to identify our priority funding needs, and support staff to communicate effectively about these priorities.
- Be audience-focused, understanding our funders, volunteers and competitor environment.
- Improve processes, monitoring and efficiency to maximise impact, develop sustainable income and manage risk.
- Be proactive and responsive to changes, learnings, challenges and opportunities.

To be well governed and well led

- Consolidate and build strong leadership.
- Conduct ourselves at all times with integrity.
- Make decisions based on sound evidence and with due regard to risk.
- Ensure we are an effective Board.
- Represent our community.
- Be open and accountable at all times.

To educate, innovate and research

- Be recognised as a knowledge hub and centre of expertise.
- Be the organisation of choice for staff and volunteers.
- Develop a talented, efficient and productive organisation.
- Lead and partner in research and innovation.

To attract, retain and engage our people, valuing difference

- Be an employer of choice, attracting the right people from a range of backgrounds into the right jobs at the right time.
- Operate a reward and benefits scheme that is fair, competitive and sustainable.
- Create an environment where everyone, regardless of background and ability, can develop mutually beneficial skills, knowledge and behaviours.
- Be an organisation that retains great talent and attracts people back.
- Value our people for the contribution they make and create an environment where people give their best.

Strategic enablers

To communicate effectively

- Develop our brand and brand positioning.
- Develop our understanding of our audiences, and be audience-focused in our choice of communication channels, activity and messaging.
- Be proactive and responsive to changes in the external environment.
- Measure impact of our communications and use learnings to inform future activity.

Maximise the use of data

- Support more informed decision making by the Board, managers, teams and individuals at all levels.
- Provide more transparent, effective and timely reports to influence and provide assurance to the Board, Commissioners and funders.
- Enable evidence-based discussions with our Board, managers, teams and individuals at all levels.

Utilise our resources well, maximise digital technology and give due consideration to sustainability

- Implement our IT Strategy to ensure staff have the technology and training in place to perform effectively and efficiently.
- Review our expenditure, both during the year and during budget setting, to ensure we are achieving value for money.
- Investigate areas of income diversification and seek opportunities to reduce our income risk.

To listen, learn and act

- Ensure we actively listen to the public, patients and families, supporters, stakeholders, staff and volunteers.
- Develop new ways of gaining feedback.
- Be open and honest about where we can improve.
- Take quick action when we learn and embed that learning across the organisation.



We deliver better outcomes by **working together**.



We take **care** of each other.



We can be **trusted** and are **respected** for our **professionalism**.



We are **committed** and **innovative**.

Welcome to Keech Hospice Care for Adults and Children. This pack contains information to help guide you through your placement, and to give you a clearer understanding of our Strategy, our Values and our history.

We hope you enjoy your time with us at Keech Hospice Care and find it a valuable and enriching experience.



A History of Hospice Palliative Care Services

The modern-day hospice movement came into being in 1967 when Dame Cicely Saunders founded St. Christopher's House in London. However, hospice care goes back to the mid-1800s.

In 1843, as a young widower and bereaved mother, Mme Jeanne Garnier, along with others in a similar situation, founded the Dames de Calaire in Lyon, France, to provide care for the dying. At that time death was seen as a failure by the medical system and consequently the focus of hospitals was on curative treatment – the dying were not welcomed.

Between 1874 and 1899, twenty-one years after her death, Jeanne Garnier's influence led to the introduction of six more establishments in Paris and New York.

Thirty-six years after the first hospice was founded, the idea spread to Ireland when it was adopted by The Irish Sisters of Charity who opened Our Lady's Hospice in Dublin. Shortly after, it spread to England when they opened St. Joseph's Hospice in Hackney, London.

However, hospices did not become more widely known until Dame Cicely Saunders founded St. Christopher's House in London in 1967.

Cicely Saunders, born in 1918, was trained as a nurse and then as a social worker. During her work in a hospital she became aware of the psychological and spiritual needs of dying people, who often felt isolated and alone. As a social worker, Cicely Saunders met a patient, a Polish Jew called David Tasma. He asked her for "what is in your mind and in your heart".

As he was dying with cancer and had pain, vomiting and other symptoms, she became interested in the medical treatment for cancer, especially the treatment for pain control.

For that reason, she started medical training and qualified as a doctor in 1957.

Listening carefully to her patients and their stories of illness and suffering she created the concept of "total pain". The other important fact was that she had an opportunity during her work as a volunteer in St. Joseph's Hospice to use strong opioids and to see that "constant pain needs constant control". It means that analgesics should be given regularly to prevent pain, not on demand to alleviate it.

Using her experiences as a nurse, social worker and a doctor, she integrated all her skills and opened the first modern hospice, St. Christopher's Hospice in London. This hospice, named after the travellers' protector Saint Christopher, combined the tradition of the middle age hospices with all the modern achievements of medicine, in order to relieve the suffering of terminally ill patients and their families

The modern-day hospice movement was born and with it came local, independent charitable hospices across the UK. Today there are more than 220 hospices.

National charitable organisations Marie Curie Cancer Care and The Sue Ryder Foundation also played an important role in the provision and ongoing development of care for the terminally ill and their families. In the 1950s, 11 Marie Curie Homes were developed, and Sue Ryder Homes began to emerge in the 1970s.

At the same time as Sue Ryder was establishing provision another household name entered the scene: Macmillan Cancer Relief.

Since then, all three national charities and the local, independent charitable hospices have developed their services in line with patient needs and today, hospice care comes in many forms, all with the patient and their family at its heart.

A History of Children's Hospices in the UK

Helen House in Oxfordshire was the world's first children's hospice. It opened in November 1982. Helen House sprang from a friendship between Sister Frances Dominica and the parents of a seriously ill little girl called Helen, who lived at home with her family but required 24-hour-care.

The first children's hospice in Scotland Rachel House, run by Children's Hospice Association Scotland opened in March 1996.

There are now 54 operational children's hospice services across the UK.

A History of Keech Hospice Care



1986

In 1986 the idea of a hospice for terminally ill adults in South Bedfordshire was instigated by Dr. 'Wink' White, a local retired GP.

1991

After five years of planning and fundraising, what was then called the Luton & South Bedfordshire Hospice was built on land generously donated by Mrs Betty Robinson and became operational in April 1991. The building was later extended to create a new, purpose-built day hospice called the Powdrill Centre.

1997

In 1997, the charity launched a £3 million appeal to build a second hospice for children with life-limiting illnesses and their families, initially from Bedfordshire and Hertfordshire. Today the children's hospice also cares for children in Milton Keynes.

2000

Land for the building was again given by Mrs Robinson and a local businessman, Mr Dennis Keech, boosted the appeal with a £1 million donation. Keech Cottage Children's Hospice was officially opened by HRH The Princess Royal in March 2000.

Since then, the charity has continued to develop and improve the services it offers to patients and their families across both hospices.

2002

In 2002, work on a specialist hydrotherapy pool was completed, linking the two hospices together.

In the same year, the organisation was renamed 'The Pasque Charity'. The name, which was chosen with the locally grown Pasque flower in mind, was also applied to the Pasque Adult Hospice. The children's hospice retained its association with its major benefactor with the name Keech Cottage.

2008

In 2008, the charity began a project to upgrade the adult hospice. Much had changed in palliative care since the adult hospice first opened its doors and the original building was beginning to show its age and limitations for modern care. At around the same time the government made funds available to adult hospices to improve their buildings. The timing couldn't have been better. The charity applied for funds to rebuild the adult inpatient unit. The state-of-the-art facility was designed to better accommodate

modern practices in medical and nursing care and promote maximum levels of comfort and dignity for patients.

2009

The unit opened to patients in October 2009.

On 1st October 2009, the charity changed its name to 'Keech Hospice Care'. Working under the umbrella name 'The Pasque Charity' with two separate names for each hospice had been problematic and confusing. The new name was chosen to reflect the strongest elements of the charity's previous identities – Keech because this was highly recognised in the community; Hospice because this clearly describes the charity's work; and Care because this is at the centre of the hospice's values.

2010

In 2010, the government released a second round of funding - this time for adult and children's hospices to improve their buildings and equipment. Once again, the charity applied but didn't receive as much as it needed but did get sufficient to refurbish and enlarge the old laundry and complete renew and enlarge the old day hospice. The Day Hospice then became known as the Keech Palliative Care Centre (KPCC) to reflect the wider variety of services it now provides as well as the traditional day hospice care.

2013

In 2013 the charity was pleased to receive funding to refurbish the old kitchen, boilers, dining room and reception - the final part of the plan dreamt up in 2008!

2014/15

These refurbishment works were completed in 2014.

Going forward and subject to funding, the focus is to improve and extend services and facilities for relatives, friends and visitors of patients using either hospice. From that first idea back in 1986, Keech Hospice Care today has grown into one of the region's most respected and supported charities.

What is Palliative Care?

Palliative Care as the World Health Organisation recognised, is the active, total care of patients whose disease no longer responds to curative treatment and for whom the goal must be the best quality of life for themselves and their families.

Palliative care is now a distinct medical specialty in the United Kingdom. It focuses on controlling pain and other symptoms, easing suffering and enhancing the life that remains. It integrates the psychological and spiritual aspects of care to enable patients to maintain their dignity for the rest of their life, however imminent that may be.

Support is offered to the family both during the patient's illness and their bereavement. Support is often needed from the initial stages of the illness.

Palliative care neither hastens nor postpones death. It recognises a patient's right to spend as much time as possible at home and takes a holistic approach to care wherever the patient is.

In its modern form, hospice care in Britain forged its links with the NHS and has begun to exert a considerable influence on conventional medicine.

In summary:

- Affirms life and regards death as a normal process
- Neither hastens or postpones death
- Provides relief from pain and other distressing symptoms
- Uses a holistic approach supporting the physical, spiritual, psychological and social needs of the patient and their family
- Offers a support system to help patients live as actively as possible until death

Offers support to families to help them cope with the patient's illness both pre and post bereavement

What is Children's Palliative Care?

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond.

It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support.

Palliative care can be introduced at any point throughout a child's life; it is completely individual. Some children may require palliative care from birth; others only as their condition deteriorates.

Families may also vary as to whether they wish to pursue treatments aimed to cure or significantly prolong life.

In practice, palliative care should be offered from diagnosis of a life-shortening condition or from recognition that curative treatment for a life-threatening condition is not an option. However, each situation is different, and care should be tailored to the individual child.

Link nurses, tutors and mentors

You will be allocated a mentor for the duration of your placement. To get the best from your time here at Keech Hospice Care try to organise your shifts so that you are working with the mentor assigned to you.

Children's Inpatient Unit Link Nurse (Children's nursing students)	Clair Trueman clair.trueman@keech.org.uk Ext 871
Adult Inpatient Unit Link Nurse (Adult nursing students)	Shirley Gadsden sgadsden@keech.org.uk Ext 821
University of Bedfordshire Children's Nursing Link Tutor	Stephen Bilham stephen.bilham@beds.ac.uk 01582 743785 / 07714 272718
University of Bedfordshire Adult Nursing Link Tutor	Chris May Christopher.May@beds.ac.uk
University of Hertfordshire Children's Nursing Link Tutor	Sheila Roberts s.a.roberts@herts.ac.uk
University of Bedfordshire Paramedic Science Link Tutor	Allan Sunderland Allan.Sunderland@beds.ac.uk 01582 743077
University of Hertfordshire Paramedic Science Placement Co-ordinator	Paul Power p.power@herts.ac.uk 01707 285108
University of Hertfordshire Paramedic Science Programme Lead	Su Boardman s.boardman2@herts.ac.uk 01707 284679



Potential Learning Opportunities During Your Placement

- Observe and participate in the admission and discharge process of a patient
- Observe and participate in the physical and psychological care of a dying patient and daily care for patients with life limiting conditions
- How we assess symptoms of pain, nausea, terminal agitation, breathlessness and anxiety and how we treat them
- Plan, implement and evaluate holistic care
- Attend multi-disciplinary meetings
- Observe inter-agency working
- Work with community nursing staff and palliative care support workers outside of the Hospice building
- Participate in the administration of medication and gain an awareness of the common medications used in palliative care
- Spend time with our Supportive Care services to gain an insight of the work that they do

- Gain an insight into complex conditions, patients with co-morbidities and specific treatments
- Observe Hydrotherapy for patients/Join in an Aquatic therapy session
- Observe/participate in one of the Independence and Well-being groups to improve understanding of palliative rehabilitation.
- Observe the use of complimentary therapy
- Attend MDT, clinics or visits with the Rare Neurological Conditions Service
- Participate in caring for the deceased patient
- Spend time in our Day services across Adult's and Children's care
- Understand the need for our Palliative Care Advice Lines across the service
- Observe the work of the My Care Coordination team
- Learn the principles of Advance Care Planning
- Observe the importance of Play
- Introduction to how the independent/voluntary sector works with statutory organisations

Library Services at Keech Hospice Care

Staffing

Chris Napper, Librarian (Mondays and Thursdays 10.00 - 3.30)

Kathy Morris, Library Volunteer (Tuesdays 9.30 - 3.30)

Andrea Tween, Library Volunteer (Mondays or Tuesdays)

Location and Access Arrangements

The Library is in the old Adult IPU, next to the adult social work office. It is always accessible, please ask a staff member if you require access out of hours.

To open the Library door, pull it towards yourself as you turn the key. When you leave, **please check that you have the key with you before closing the door** as the door locks automatically when closed.

The Library Office is next to the photocopier. There is also a study area behind the photocopier.

Library Catalogue

Click on <https://u009606.microlibrarian.net> to search the catalogue for books and other resources, or you can use the Keech Library Catalogue icon that should be on the desktop of all networked computers. You do not need to log in to be able to search but logging in allows you to do things like seeing what books you have out on loan, renewing any that are overdue, reserving books and creating your own personal book lists. Please contact the library staff for your login details.

Journals

Several journals are held by the Library, including some that are available electronically. See the list below for details

 [Journals in Keech Hospice Library October 2018.doc](#)

Journal Articles

We can also get hold of articles from other journals for you. Just send the details to cnapper@keech.org.uk

Literature Searching

We can also help with literature searching to see what articles have been published on a topic, or if you feel confident you can do it yourself.

<https://www.hospiceuk.org>

<https://www.togetherforshortlives.org.uk>

<https://www.ncpc.org.uk>

<https://www.nice.org.uk>

<https://www.raredisease.org.uk>

<https://www.nmc.org.uk>

Transforming hospice care – A five-year strategy for the hospice movement 2017-2022

(Hospice UK, 2017)

<https://www.hospiceuk.org/docs/default-source/about-us-documents-and-files/hospice-uk-strategy-2017-2022.pdf?sfvrsn=6>

Care of dying adults in the last days of life (NICE, 2015)

www.nice.org.uk/guidance/ng31

End of life care for infants, children and young people with life-limiting conditions: planning and management (NICE, 2016)

www.nice.org.uk/guidance/ng61

Professional Guidance on the safe and secure handling of medicines

Royal Pharmaceutical Society (Dec 2018)

<https://www.rpharms.com/recognition/setting-professional-standards/safe-and-secure-handling-of-medicines/professional-guidance-on-the-safe-and-secure-handling-of-medicines>

Professional Guidance on the Administration of Medicines in Healthcare Settings

Royal Pharmaceutical Society/Royal College of Nursing (Jan 2019)

<https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Professional%20standards/SSHM%20and%20Admin/Admin%20of%20Meds%20prof%20guidance.pdf?ver=2019-01-23-145026-567>

Ambitions for Palliative and End of Life Care

A national framework for local action 2015-2020

www.endoflifecareambitions.org.uk

The Association of Paediatric Palliative Medicine Master Formulary (4th edition) 2017

www.appm.org.uk

Controlled drugs: safe use and management (2016)

www.nice.org.uk/guidance/ng46

The NHS Long Term Plan (2019)

www.longtermplan.nhs.uk

Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care (DoH, 2016)

<https://www.england.nhs.uk/eolc/>

Talking about dying: How to begin honest conversations about what lies ahead (2018)
Royal College of Physicians
<https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead>

Books (available in the Library)

General

Costello, J. ed. Adult Palliative Care for Nursing, Health and Social Care. SAGE, 2019
(*on order for the Library*)

Walshe, C. ed. Palliative Care Nursing: principles and evidence for practice. 3rd ed. Open University Press, 2018
(*Library class number 616.029*)

Nicol, J. & Nyatanga, B. Palliative and end of life care in nursing 2nd ed. Learning Matters, 2017
(*Library class number 616.029*)

Amery, J. A really practical handbook of children's palliative care: for doctors and nurses anywhere in the world. Lulu, 2016
(*Library class number 616.029*)

Brown, M. Palliative care in nursing and healthcare. SAGE, 2016
(*Library class number 616.029*)

Twycross, R. & Wilcock, A. eds. Introducing palliative care. 5th ed. Palliativedrugs.com, 2016
(*Library class number 616.029*)

Faull, C. & Blankley, K. Palliative Care. 2nd ed. Oxford University Press, 2015
(*Library class number 616.029*)

Ingleton, C. & Larkin, P.J. eds. Palliative Care nursing at a glance. Wiley Blackwell, 2015
(*Library class number 616.029*)

Sadler, C. ed. A practical guide to end of life care. Open University Press, 2015
(*Library class number 616.029*)

Du Boulay, S. & Rankin, M. Cicely Saunders: the founder of the modern hospice movement. Updated ed. SPCK, 2007
(*Library class number 362.17*)

Clark, D. et al. A bit of heaven for the few? An oral history of the modern hospice movement in the United Kingdom. Observatory Publications, 2005
(*Library class number 362.17*)

Communication

McCabe, C. & Timmins, F. Communication skills for nursing practice. 2nd Ed. Palgrave Macmillan, 2013 (*Library class number 610.696*)

Fearnley, R. Communicating with children when a parent is at the end of life. Jessica Kingsley, 2012 (*Library class number 155.9*)

Lambert, V. et al. eds. Communication skills for children's nurses. Open University Press, 2012
(*Library class number 610.696*)

Dunphy, J. Communication in palliative care: clear practical advice, based on a series of real case studies. Radcliffe, 2011
(*Library class number 610.696*)

Spiritual & Religious Care

Goodhead, A. & Hartley, N. Spirituality in hospice care: how staff and volunteers can support the dying and their families. Jessica Kingsley, 2018
(*Library class number 291.17*)

Nash, P. et al. Multifaith care for sick and dying children and their families: a multidisciplinary guide. Jessica Kingsley, 2015
(*Library class number 291.17*)

Neuberger, J. Caring for dying people of different faiths. 3rd ed. Radcliffe Medical Press, 2004
(*Library class number 291.17*)

Bereavement

Gross, R. The Psychology of Grief. Routledge, 2018
(*Library class number 155.9*)

Wilson, J. Working with bereavement: a practical guide. Palgrave Macmillan, 2014
(*Library class number 155.9*)

General Information

Shift Times		
Children's Inpatient Unit (CIPU)	Long Day	07.30am-20.00pm
	Night	19.30pm-08.00am
Children's Community & Day Support Services	09.00am-17.00pm Mon-Fri (with 24hr on-call nurse cover available)	
Adult Inpatient Unit (AIPU)	Long Day	07.30am-21.00pm
	Early	07.30am-15.30pm
	Late	13.00pm-21.00pm
	Night	20.30pm-08.00am
Keech Palliative Care Centre (KPCC)	09.00am-17.00pm Mon-Fri	
Supportive Care	09.00am-17.00pm Mon-Fri	
My Care Co-Ordination Team (MCCT)	08.00am-17.00pm Mon- Fri 09.00am-17.00pm Weekends PCSW's: 16.00pm-22.00pm Mon-Fri 09.00am-21.00pm Weekends/Bank Holidays	
Independence & Wellbeing Service	09.00am-17.00pm Mon-Fri	

Uniform

The Hospice Uniform Policy is available on the Keech Intranet. If you are required to wear Uniform whilst on placement, please wear the uniform provided by your University. The exception is Paramedic Science students who are not required to wear uniform whilst on placement at Keech Hospice Care. Dress should be smart casual office wear, no denim or trainers. Trousers are often preferable for students given the nature of some patient activities. Paramedics science students from the University of Bedfordshire should wear their polo shirts.

Sickness Absence

If you are unwell during your placement, please telephone your contact at Keech Hospice Care to advise as well as the usual process at your University.

Refreshments

Tea, Coffee and soft drinks are provided free of charge throughout your placement at Keech Hospice Care. There is a restaurant on site, Valerie's where food and drink may be purchased.

Care Directorate

Adult In-patient Unit (AIPU)

The Adult In-patient Unit (AIPU) is an eight-bedded unit that provides 24-hour specialist palliative care for patients who live in Luton and South Bedfordshire and have a palliative diagnosis.

The service aims to provide support and advice to community services and the Acute Trust. The AIPU's Senior Sister is a core member of the specialist palliative multidisciplinary team (MDT).

Referral Criteria

Any adults over 18 years of age registered with a GP in Luton and South Bedfordshire who have a diagnosis of a progressive, life-limiting disease and are in the palliative stage of their illness are eligible for referral. They will be symptomatic with difficult or complex psychological, social, spiritual issues and specialist palliative care needs.

All referrals to the AIPU are made by health care professionals such as:

- Macmillan Specialist Nurse;
- Consultant;
- GPs;
- District Nurses;
- Clinical Specialist Nurses.



Admissions

The beds are managed daily by a Senior Sister/Sister or senior staff nurse. It is the responsibility of the staff member managing beds to manage admissions in accordance with the charity's Referral and Admission Procedure. The Senior Sister Community Liaison will triage referrals and assess the patient prior to admission where possible. This assessment will be documented on SystmOne. A bed may be declined if the patient does not have specialist palliative care needs after discussion with the medical team.

Discharges

All discharges are planned with the patient/community team and discussed at the weekly MDT meeting. Once discharge has been agreed:

All community services are notified and updated on patient condition
Medical team request medication (TTOs)
Transport can be arranged if needed
Nursing letter/medicine list and medical letter completed, and copy given to patient for patient held records as well as being faxed to the appropriate community services.

Patient care is then handed back over to the key worker.

Service Provision

The AIPU provide symptom management, end of life care, emotional support and support for carer breakdown.

The AIPU has eight single bedrooms with four shared bathrooms. There is accommodation for families to stay either in a separate family suite (including en-suite bedroom and lounge) or by the patient's bedside.

A specially designed cool room, named the Pasque Room, is available on the unit where a patient can be placed after death in the air-conditioned room and families are welcome to visit until the undertaker arrives. No patient will occupy the Pasque Room for longer than 24 hours.

My Care Co-ordination Team (MCCT)

MCCT is a service that provides co-ordination of palliative patients' care. This is for those adult patients (aged 18+) with any life-limiting illness who are thought to be in the last two years of life and registered with a Luton GP. The service provides a 24 hour, 365 days a year phone line. MCCT cover 08:00 to 17:00 Monday to Friday, 09:00 to 17:00 weekends and bank holidays, with an urgent response PCSW 16:00 to 22:00 on weekdays and 09:00 to 21:00 at weekends and on bank holiday. The service also provides an end-of-life locality register.



Aim of service

Who provides the service? MCCT comprises of 4 whole-time equivalent (WTE) senior administrative staff with a background in healthcare and excellent IT and database skills.

The PCSWs are a 2 WTE team of healthcare assistants with extended training and experience in palliative and end-of-life care. The team is managed and led by a 0.8 WTE senior nurse.

Keech Hospice's Supportive Care team will provide the pre- and post-bereavement support to all patients, relatives and carers who require this service.

Who is the service for? For all patients aged 18+ registered with a Luton GP who are considered to be in their last year or two of life.

Referrals

Referrals can be received from the patient or health and social care professionals. Professionals can make a referral, once gaining patient consent face to face, via the telephone or after making a ‘best interests’ decision, via electronic referral system on SystmOne or by e-faxing a MCCT consent form.

Requests for a PCSW visit can be made by the keyworker, community nurse, Macmillan nurse, hospice nurse, integrated discharge planning team, or social worker. If the request is from a patient or their relative, the Care Co-ordinators will liaise with the keyworker.

Keech Palliative Care Centre (KPCC)

Keech Palliative Care Centre (KPCC) is a specialist palliative outpatient unit providing specialist palliative care for adults with a life-limiting illness who are registered with a GP in Luton and South Bedfordshire.



The service will adopt a collaborative, multidisciplinary team approach across all internal and external service providers, to enable patients to make informed choices about the care they receive and to maintain an optimum quality of life until death, whilst also supporting their family, friends and carers during the changing phases of their illness.

Referral Criteria

The service is available to any adult over 18 years of age who meets all the following criteria:

- is registered with a GP in Luton or South Bedfordshire
- has an active, progressive life-limiting disease
- has a complex level of need
- requires additional palliative care support above that provided or available from primary care and community supportive services

All referrals to KPCC are made by health care professionals such as:

- Palliative Clinical Nurse Specialists
- Consultant
- GPs
- Community Nurses
- Speciality Clinical Specialist Nurses
- Occupational Therapists
- Physiotherapists
- Speech and Language Therapists

Referrals from health care professionals are received and processed by a member of the My Care Co-Ordination Team and are responded to within five working days. The referrer will be contacted to acknowledge receipt of the referral to the service. The patient will be contacted within seven working days and offered an appointment to attend an assessment in the Nurse Led Clinic. Where there is concern about appropriateness of the referral, contact will be made with the referrer to gather more information in the first instance. Any referral that is deemed inappropriate will be discussed at the internal Multi-Disciplinary Team (MDT) meeting on a Tuesday morning and a supportive plan for signposting to alternative services agreed. Once a decision has been taken the referrer will be contacted and informed of the MDT's decision.

On admission to the service, a holistic assessment and individualised plan of care which addresses the patient's physical, psychological, social and spiritual needs will be undertaken. This plan is developed with the agreement of the patient and their family and will be continuously reviewed and evaluated with their involvement throughout their contact with the service. Patients may attend for outpatient appointments only, for drop-in sessions or for long days, or a combination of any of these, depending on the outcome of the assessment. Transport will only be offered if there is no other means of getting to KPCC. Attendance is flexible according to need but will be the same day

in any week to facilitate continuity of care with the professionals involved.

Patients may be offered up to six weeks supportive care and discharged back to their key worker following review. A further six weeks of care is offered if an ongoing need is identified.

Patients who attend regularly are reviewed using the Palliative Outcome Score on weeks 1, 3 and 5. In addition, goals set at initial assessment are reviewed at week 5.

If circumstances change, such as the patient's phase of illness deteriorating, the patient's attendance can be reviewed, and additional attendance can be extended depending on assessment of the patient's current individual needs.

KPCC runs as an out-patient facility within the hospice. It provides specialist palliative care services for patients with palliative conditions. This incorporates Carers Support, Drop-ins, Day Service, Doctors Clinic, Nurse Led Clinics, and if appropriate, complementary therapy, music therapy, art therapy, 1:1 support, Independence and Well-Being Service (occupational therapy/physiotherapy) and hydrotherapy (only if patient has been deemed medically fit to access the pool).

KPCC can also undertake specific medical treatments such as blood transfusions, venepuncture and bisphosphonate infusions.

Independence & Well-being Service

The Independence and Well-being service is a joint service by Keech Hospice Care and Macmillan Cancer Support and is about living well for longer. Ensuring that patients have the professional support they need, and choice and dignity they deserve. They support and educate patients to self-manage their condition, to understand its progression and aim to improve quality of life.

Any adult in Luton and south Bedfordshire with a long-term, palliative condition can be referred to the Service by their GP, consultant or specialist nurse.

Palliative rehabilitation can help improve and ease many symptoms including breathlessness, pain, fatigue, reduced mobility and physical activity, low mood, altered body image, loss of identity/role and the lasting effects of treatment.

Patients will be contacted directly following referral to arrange a one-to-one appointment to discuss goals and expectations. The team will put together a package

of care and support tailored to the patient and their needs. Patients will learn practical ways to manage their condition to enable them to remain as independent as possible.

The Service offers three groups: Move, Music and Mind; Strength in Numbers and Walking and Well-being. These groups are intended to get patients moving, thinking and socialising in a supportive, safe environment.

Rare Neurological Conditions Service

The RNCS was set up two years ago in response to a lack of specialist understanding of the management of rare and complex, progressive neurological conditions. The service offers support to patients aged 18 + (will also support patients in transition 16 - 17yr olds), diagnosed with any rare progressive neurological condition (not Multiple Sclerosis or Parkinson's Disease), genetic or sporadic, who are registered to a Luton GP. It is run by the Specialist Neurological Coordinator, who is a Clinical Nurse Specialist by back ground and supported by the Neurological Link Nurse. The service is available 0900 – 1700hrs, Monday to Friday and patients can be seen either in the Hospital, the Hospice or in their own homes.

Aim of service

The service works closely with the wider multidisciplinary team in primary, secondary and tertiary centres to provide a pathway of care that offers a holistic needs assessment approach, with seamless, co-ordinated care to support patients from the point of diagnosis until death. It provides patients with:

- A single point of access to services and support available.
- Simplifies care access, so both patients and professionals benefit from a coordinated service and improved understanding of the role of each member of the multidisciplinary team. Monthly multidisciplinary clinics are held at Keech Hospice and monthly multidisciplinary team meetings are held at the Luton and Dunstable Hospital.
- Patients are empowered to make informed choices about their care, with knowledge about who will help and when, overall enhancing their quality of life and service usage.
- Ensure that all appropriate service providers are informed about the disease, the resources available and the circumstances of those affected by a rare and

rapidly progressing neurological condition, enabling an effective response in a 'needs led timescale' and promoting professional education.

- Specialist symptom control and resource for health and social care professionals.



Service Outline

The main conditions supported are Motor Neurone Disease, Huntington's Disease, Progressive Supranuclear Palsy and other related atypical (life limiting) Parkinson's conditions, Lewy Body dementia, rare genetic conditions such as Leighs Disease, Spinal Muscular Atrophy and any other rare and/or complex, neurological condition that does not have an existing specialist service available.

Referral is usually from the Consultant Neurologists, but anyone can refer to the service, including direct referral from patients/families.

Medical Team

Keech Hospice Care has a dedicated team of Doctors who provide 24 hour a day cover to the Hospice. Our doctors are registered practitioners with training and experience in palliative care. They provide assessment and management of individual care needs agreed with the patient and their family.

Clinical Education Team

The Clinical Education team is based on-site at the Hospice. The team is comprised of a Clinical Development Lead who leads on all internal clinical education and development for staff, a Lecturer Practitioner who focuses on external clinical palliative education across Luton and a Practice Educator based in Adult Services.

The wider education team also consists of a Learning & Development Officer and a Hospice Librarian.

The Clinical Education team are based close to the Hospice library and will assist in co-ordinating student placements across the Care Directorate.

Children's Services

The Children's Service team provides 24-hour specialist palliative care and support to children aged 0-19 years and their families that meet the referral criteria using a flexible and responsive approach. It also acts as a specialist paediatric palliative health care resource, giving advice to healthcare and allied professionals.

The service aims to enable children to live their lives to their full potential throughout their illness, providing holistic assessment, support and advice. All elements of the service (i.e. in-house, day support, social work, supportive care and community nursing) aim to offer a seamless service to all families.

Referral to Children's Services

Children and young people are initially referred to the whole hospice service and not individual elements of the service. New referrals are usually discussed at the weekly in-house multidisciplinary team (MDT) meeting. An assessment of family need will be carried out once the referral has been accepted. If a referral is urgent a decision will be made outside of the internal MDT meeting. Any professional or parent/carer can refer a child to Keech Hospice Care; referrals are made on the Keech Hospice Care referral form.

All clinical nursing staff are aware of how to manage both routine and urgent referrals. The service administrators will ensure that new referrals are entered onto SystmOne, the electronic patient record system used at Keech Hospice Care.

Children's Services Referral Criteria

Any child under the age of 19 years living in Hertfordshire, Bedfordshire or Milton Keynes who has a life limiting condition is eligible for referral to the Children's Service. Referrals for young people aged 17/18 years old who are not requiring end of life care will be considered by the multi-disciplinary team based on individual need at the point of referral and the services required to meet those needs. It is likely that young people of this age will have already transitioned into adult services for most of their care needs and it may be more appropriate for Keech Hospice Care to signpost these young people and their families to other services.

A life-threatening condition is one in which medical intervention may prove successful but by its nature carries a substantial chance of mortality in childhood (ACT/RCPCH 2nd edition, 2003).

A life limiting condition is one for which there is currently no cure available and the likelihood is that the condition will lead to the child dying prematurely (Sutherland, Hearn, Baum & Elston, 1994).

ACT and the RCPCH (2003) suggest that there are four groups of condition:

1. Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment are not included, e.g. cancer.
2. Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, e.g. cystic fibrosis.
3. Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years, e.g. Battens disease, muscular dystrophy.
4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complication and likelihood of premature death, e.g. severe cerebral palsy.

The Children's Service has developed a Paediatric Referral Criteria checklist for use in the weekly MDT meeting to aid decision making when considering whether children meet the referral criteria for addition to the caseload.

There are several teams that provide care to children and their families at Keech. These are:

- Children's In-Patient Unit (CIPU) Team
- Community Nursing Team
- Day Support Team
- Supportive Care Team
- Social Work Team

Children's In-Patient Unit Team



The CIPU Team provide end of life care, symptom management, emotional support, crisis care, short breaks and transition from hospital to home care for children and their families.

CIPU has five beds in four bedrooms and there is accommodation provided for families to stay on the unit. In addition, there is a bereavement suite, named the Meadow Suite, with a chilled bedroom and bed for the deceased child.

Community Nursing Team



The Community Nursing Team is the initial point of contact at the hospice for children and families following referral. They will facilitate an initial assessment of the child and family and internally refer to other services as appropriate. The community nurses will act as a 'key worker' for the child's hospice care and assist in navigating them through their hospice journey.

The Community Nursing Team offer end of life care, symptom management, nursing care, 24-hour 'on call' support, support and advice, liaison work, pre- and post-bereavement support and memory work. This is provided by nurses, Palliative Care Support Workers and a Community Play Specialist in a variety of settings, based on individual assessed need, including the family home, school, hospital, etc.

The Community team workload is prioritised using a Red, Amber, Green rating.

There is a Palliative Care Support Worker who specifically works with children and young people that have neuro-muscular conditions. The role offers a wide range of support mechanisms to these children and their families; including home/school visits, support groups and social activities.

Day Support Team

The Day Support Team offers a variety of support to children and their families. Support is provided both in the community and at the hospice, incorporating specialist palliative care reviews, specialist play, one-to-one support, memory work, social activities, outings and events, and access to complementary therapy, creative art therapies and hydrotherapy.

Families admitted to the service are offered 6 sessions of Day Support, scheduled in advance. Attendance is flexible according to need; sessions will be rescheduled as required.

Goals set at initial assessment are reviewed after the family's 5th session by the internal Paediatric MDT. If an ongoing need is identified, an additional 6-week programme will be offered and arranged. If an ongoing need is not identified the family will be discharged from the Day Support service.

The initial Day Support session, if held in-house at Keech, will be facilitated by the Day Support Nurse. Parents will be asked to stay for this session in order to complete Day Support clinical care plans for their child. Intended goals and outcomes for Day Support are discussed and agreed by the team and parents. Activities for day support and memory work are planned in advance where possible.

If the initial Day Support session is held in the community, it will be facilitated by one of the Play Specialists. There is no requirement for children that receive specialist play at home to have clinical care plans.

It may be possible for a child to be reviewed by a specialist doctor whilst in Day Support. Children and families can request to be seen by a specialist palliative care doctor for a variety of different reasons, including:

- Follow up after a symptom management stay in-house at the hospice;
- Symptom management or review;
- Advance Care Planning / DNACPR / end of life discussions;
- Sensitive conversations, e.g. prognostication.

Supportive Care Team

The Supportive Care team offers emotional and psychological support in pre-bereavement to all patients and their families. Post-bereavement support is available to all families and carers of patients known to Keech services.

Referrals to the Supportive Care team are through the weekly in-house MDT meetings in Adult and Children's services and through external health professionals.

All therapies are outcome focussed and offered in short blocks of time followed by re-assessment and continuation of support if required.

The Supportive Care Team is comprised of several specialist services, as follows:

Music and Art therapy is offered to all patients and their families. It is an assessed service and is dependent on therapeutic need. These therapies offer an alternative form of communicating emotions and feelings compared to talking therapy. The services can be provided on an individual basis or as part of a family or larger group. It is offered within the hospice setting or, where appropriate, in a community setting.

Complementary therapies are offered to all patients and family members and can be accessed via the Complementary Therapy Co-ordinator.

The Children's Service has a dedicated Complementary Therapist employed two days per week who offers therapy sessions specifically for children known to the service. These sessions can be offered 'in-house' or out in community settings.

The Adult service has volunteer complementary therapists covering five days a week.

Family Support Workers offer talking therapies to patients and their families. This can be delivered via one to one or group support. Bereavement volunteers are trained by the family support workers to deliver less complex support.

There are several support groups offered to families:

- Silver Lining (a monthly post-bereavement support group held in the evening at Keech which can be attended for up to two years)
- Talking Elephants (an informal monthly post-bereavement support group held externally to Keech, and is offered to anyone who is bereaved and not just Keech families)
- Dads Cry Too (a monthly post-bereavement support group for Dads who have had a child die who was known to Keech)
- Sparklers (our children and young adult support group, which is a mixture of pre and post-bereaved young people from Adult & Children's services which is held monthly on a Saturday)

Remembrance Events

The Supportive Care team are responsible for organising the three annual remembrance events held throughout the year:

- Adult Remembrance Service (held locally in May and is for families that have been bereaved of an Adult in the last 18 months)
- Children's Remembrance Service - Daffodil Sunday (held at the Hospice in September for families who have been bereaved of a child in the last 18 months)
- Light up a Life (held at the Hospice in December and is open to everyone including those not known to Keech)

Hospice at Home

The Hospice at Home service has highly trained volunteers that visit patients and families at home. This gives the patients someone to listen, talk or read to them, or simply sit should they wish to sleep. It can also enable carers to take time out from their caring role. Our volunteers with permission can take patients out. Volunteers visit once weekly for approximately two hours.

The Hospice at Home co-ordinator initially visits to assess individual needs of the patient and/or their carer. A suitable volunteer will be identified and introduced to the client by the co-ordinator.

Hydrotherapy Pool

Keech Hospice Care is fortunate to have a hydrotherapy pool and encourages its use whenever appropriate for therapeutic purposes.

The hydrotherapy pool is very different to an ordinary swimming pool. The water temperature is maintained at a higher rate (up to 35°C) to stimulate circulation and relaxation; and to allow frail patients, with poor temperature control, the opportunity to experience water activities. The air temperature is also controlled to avoid the 'shiver' effect and coldness when getting out. There is special filtration equipment and a water treatment unit to ensure the water is perfectly clean for users who may be frail.



In addition, there is sensory stimulation equipment (underwater lights, music system, etc.) to relax and reassure the user and to make the whole experience enjoyable.

Because it is a dedicated facility, the numbers that use the pool at one time and the activities that are arranged, can be controlled and tailored to the needs of the individual. For example, an apprehensive hospice patient could have their session alone in the pool if necessary.

We have an employed Senior Lifeguard and a team of volunteers who supervise the pool.

Social Work

Children's Services

Social work support is available to all families on a short term or on-going basis dependent on need. This is offered in conjunction with Local Authority social care.

The children's palliative care social worker and social work assistant are employed directly by the charity, providing specialist independent advice and support to children and their families from a social care perspective.

The social worker can advise families on practical and financial matters, focusing on aspects such as benefits, housing, education, social activities, holidays, wishes and transition. The social worker/assistant can liaise with other agencies as necessary

alongside helping families deal with the emotional and psychological consequences of caring for a child with a life-limiting illness.

After a child has died, the social worker/assistant can continue to offer bereavement support to the whole family as appropriate alongside the Keech Supportive Care Team.

Adult Services

The adult palliative care social worker and social work assistants are employed directly by the charity and are there to provide both practical advice and support, as well as providing a high level of emotional and psychosocial support to patients, and their families and carers.

Palliative care social work can help patients and families with planning for the future, in terms of what is realistic and practical, and what meets the patient and family's needs. The social workers provide a 'social model' of care perspective to the MDT, and advocate for the 'social' aspects of the patient's care, within MDT meetings and discussions.

They work with complex family situations and help support families to talk about the most difficult issues facing them, such as future planning, wills, and advance care planning.

The social workers are the front-line main contacts for safeguarding matters that arise at Keech. Social workers work to empower individuals to meet their aspirations and needs and work with people to help them maximise their quality of life and interests.