Support for People Affected by a Life Limiting Illness

Services available and the care you should expect from health and social care staff looking after you and your family.
Being told that you or someone you love and care for has a life limiting illness that cannot be cured is tough news to receive.

The care that you need at this time will be focused upon supporting you to have the best possible quality of life, your independence and control – this will help you when it comes to being able to make choices. This care is called palliative or end of life care.

Palliative and end of life care is about treatment and care focusing on the needs of the whole person as well as their relatives, carers and friends. It is not just about managing pain and other physical symptoms but includes support to deal with:

- Emotional needs
- Social and spiritual needs
- Care in bereavement
- Help to deal with the financial effects

Everyone responds differently to having a life limiting illness, and every individual will have different needs for information, support and advice.

There may be questions which would be helpful to talk through. It is natural to feel sad or upset; you may not want to talk to anyone about how you feel. Your family and friends will also have a range of feelings.
What standards of care should I expect?

We wish to make sure that the care and support given to people affected by a life limiting illness is high quality, reliable and consistent, health and social care staff in Great Yarmouth and Waveney work to the following care standards:

• To be treated with dignity and respect by all who care for me

• To be cared for using nationally recognised care tools (Advance Care Planning, the Gold Standards Framework and the Liverpool Care Pathway)

• To be involved in decision making about my care, both now and in the future

• To know who to contact for help and support 24/7

• To be offered emotional support

• To be offered choice about my place of care/death

• For my family to be supported to care for me at home if this is where I want to be and it is safe to do so
What help is available?

1. Help with symptoms of my illness
   • Talk to your current health/social care team, e.g. your GP, District Nurse, Consultant or Specialist Nurse at the hospital.
   • One of the team may also ask a member of the Specialist Palliative Care Service to provide expert advice and support about the assessment and management of symptoms. You can also refer yourself to the Specialist Palliative Care Service if you wish.
   • If you have nursing care needs you can self-refer to the District Nursing Service. “Respite” care can also be organised to give your family a break if they are looking after you at home.

   Specialist Palliative Care Service -
   Tel: 01493 452804/453439 - Monday to Sunday 9am - 5pm or the James Paget Hospital switchboard - Tel: 01493 452452
   Tel: 0800 56 70 909 - Monday to Sunday 5pm - 9am

   District Nursing Service -
   Tel: 01493 453301

2. Practical support at home
   • Social care at home can be organised via Adult Social Services at Norfolk and Suffolk County Councils (e.g. help with shopping or cleaning at home).

   Norfolk County Council -
   Tel: 0344 800 8014 - Adult & Children Social Services

   Suffolk County Council -
   Tel: 0808 800 4005 - Customer First service
3. Financial support and advice

- You can get financial and benefits advice from the Citizen’s Advice Bureau and the Macmillan Welfare Benefits Service (if you live in Waveney).

   Citizens Advice for Great Yarmouth & District
   Tel: 01493 856665


4. Spiritual support

- You can access spiritual support from your local community faith leaders, or if you are receiving care at the James Paget Hospital you can access spiritual support from the: Hospital Chaplaincy Team on 01493 452408.

5. Help caring for a child with a life limiting illness

- You can access help caring for a child from the community paediatric nursing service, from Quidenham Children’s Hospice and from the national charity Together For Short Lives.

   Children's Community Nursing Team (Norfolk & Suffolk)
   James Paget University Hospital, Lowestoft Road, Great Yarmouth, Norfolk NR31 6LA
   Tel: 01493 452452

   Quidenham Children’s Hospice
   Monastery House, Quidenham, Norwich, Norfolk NR16 2PH
   Tel: 0843 277 4709

   Together For Short Lives
   4th Floor, Bridge House, 48-52 Baldwin Street, Bristol BS1 1QB
   Tel: 0117 989 7820
   Helpline: (0845 108 2201)
What if I am not satisfied with my care?

It is important to talk to the health and social care staff providing your care to make sure that they understand your care needs. It is also important to talk to them if you feel there has been a problem with the care you have received.

You can also contact the Patient Advice and Liaison Service which can advise and support patients, families and carers, by providing information about NHS services and listening to your concerns. They can also help to sort out problems on your behalf.

The **PALS** service can be contacted on **01502 719501**.

If you would like to make a formal complaint, you can do so in writing to: **The Complaints Manager (PALS)**, NHS Norfolk and Waveney, Lakeside 400, Old Chapel Way, Broadland Business Park, Thorpe St Andrew, Norwich NR7 OWG

What can I do next?

If after reading this leaflet you feel that some or all of these areas are affecting you in some way and you need help to deal with them, you can make an appointment with your GP, hospital doctor/specialist nurse, district nurse, or social worker to talk about your concerns.

Or you could ring the Palliative Care Advice Service to talk it all through with a trained palliative care nurse.

**Specialist Palliative Care Service** -
Tel: 01493 452804 / 453439 - Monday to Sunday 9am - 5pm
or the James Paget Hospital switchboard - **Tel: 01493452452**
Tel: 0800 56 70 909 - Monday to Sunday 5pm - 9am

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