FAMILY’S VOICE

HELPING RELATIVES OR FRIENDS IN THE LAST DAYS OF LIFE

Information Sheet

This leaflet can be made available in other formats including large print, CD and Braille and in languages other than English, upon request.
We want to give the best care possible at this very important time. We believe the patient should be comfortable, their family satisfied and involved with the care being given.

We would like to know your views on what you see and experience. We believe only by working together we can achieve this. We would like to invite you to use the 'Family's Voice' diary. It can be completed by any family member, carers or friends.

Before you decide, we would like you to understand why this project is important to us and what it will involve from you.

**What is the purpose of this diary?**

The 'Family's Voice' is important because communication at the time of someone dying can be very difficult.

The purpose of this diary is:

- to give the best care possible
- improve communication between family and health professionals so we can care together
- give the family or friend a 'voice' at this difficult time
- provide daily feedback to staff
- provide feedback to the palliative care team.

This project is taking place on all the adult wards of this Trust. All families of patients approaching End of Life are invited to use the diary. If you wish to know more details please contact the Palliative Care Team (see contact numbers).
What will I have to do?

You are asked to complete the diary once a day or as often as you wish. **Always** leave the diary near to your relative or friend so their nurse or doctor can review it when they visit.

There are questions in the diary which focus on your relative’s or friend's pain, sickness, breathing and calmness. There are questions asking whether you feel your relative or friend is being treated in a sensitive manner and whether you feel you are being treated well.

You are invited to rate and make comments about the care and let us know if there is anything more we could do to improve future care.

Possible concerns

- **Families may feel it adds additional pressure at a difficult time.**

  We see it as a way of relieving pressure and also a way of involving you in the care of your loved one. It highlights the most important areas of care to focus on while you are visiting.

- **It could be seen as a distraction.**

  It is meant to involve you in the care but if you think it is a distraction feel free not to use the diary.

- **Some families may prefer to talk with staff.**

  This can still be done.
Families may feel a negative comment may affect the quality of care their relative or friend will receive. We can assure you this will not be the case. We take the care we give seriously. This is why we believe families' and friends' involvement is important to us and why we have developed the 'Family's Voice'.

**What will staff do?**

The feedback you give will be reviewed daily by the ward staff to identify any issues that need to be addressed immediately.

**How will the diary make a difference?**

When the diary is complete, it will be sent to the Palliative Care Team.

Your scores and comments will be checked to see if you thought the care was good enough and if the diary was helpful in improving communication. It should provide a 'snapshot' of the care provided on the ward as seen by you.

By completing the diary you will contribute to the care of your relative or friend and other patients and their families in the future.

**Do I have to take part?**

No. Filling in this diary is voluntary. You are free to stop using the diary at any time. If you decide not to take part, it will not affect the care of your relative or friend in any way.

**Will my feedback be kept confidential?**

Yes. The ‘Family's Voice’ is confidential information and will be stored with the patient's notes.
This information will be used to improve the service and any personal details will be anonymised (they would have no details which could identify you) in any report.

If you have highlighted any problems or concerns with the care and would like to be informed on how we have dealt with these issues, please provide your contact details on the back page of the diary.

The on-going development of the ‘Family's Voice’

We would like to continually improve the care of future patients and their families in this Trust. In order to achieve this we need your further feedback.

For this reason, on the back page we ask your permission to contact you at a later and less distressing time to discuss the advantages and disadvantages of this diary. Please tick the box if appropriate.

After you have read this leaflet, if there are any unanswered questions or aspects of the diary you do not understand please ask a member of the ward staff to explain. Feel free to talk to others about the diary.

Contact numbers

North Tees and Hartlepool NHS Foundation Trust

Specialist Palliative Care Team
Nurse Consultant in Cancer and Palliative Care
telephone: 01642 383895
Monday - Friday, 9.00am - 5.00pm
This leaflet has been produced in partnership with patients and carers. All patient leaflets are regularly reviewed, and any suggestions you have as to how it may be improved are extremely valuable. Please write to the Quality Assurance Team, University Hospital of North Tees or email: patientinformation@nth.nhs.uk

Comments, Concerns, Compliments or Complaints

We are continually trying to improve the services we provide.

We want to know what we’re doing well or if there’s anything which we can improve, that’s why the Patient Experience Team is here to help.

Our Patient Experience Team is here to try to resolve your concerns as quickly as possible. If you would like to contact or request a copy of our PET leaflet, please contact:

- telephone: 01642 624719
  Monday – Friday, 9.00am – 4.00pm
  Messages can be left on the answering machine and will be picked up throughout the day.

- freephone: 0800 092 0084

Email: patientexperience@nth.nhs.uk

Out of hours if you wish to speak to a senior member of Trust staff, please contact the hospital switchboard who will bleep the appropriate person.

- telephone: 01642 617617
  24 hours a day, 7 days a week

The Patient Experience Team is available to discuss your concerns in person Monday – Friday, 1.30pm – 4.30pm. The office is based on the ground floor at the University Hospital of North Tees.

Data Protection and use of patient information

The Trust has developed a Data Protection, Caldicott and Disclosure Policy (IG5) in accordance with the Data Protection Legislation (General Data Protection Regulations and Data Protection Act 2018) and the Freedom of Information Act 2000. All of our staff respect this policy and confidentiality is adhered to at all times. If you require further information please contact the Information Governance Team.

- telephone: 01642 383551 or email: information.governance@nth.nhs.uk