WHAT TO DO IF A PUPIL WITH A BRAIN TUMOUR BECOMES PALLIATIVE AND MAY DIE

Most young people with a brain or spinal cord tumour are successfully treated, but some, sadly, will die from the disease. The school community should try to create a climate where the pupil’s independence, hope and dignity are respected, and consideration given to how siblings, other pupils and members of staff may also be feeling.

Preparation before death

Nominate one key member of staff to keep in touch with the family and coordinate information and support, taking the lead from the family about who this is and what can be shared – who should be told, what, when and how - including considering how much the pupil her/himself may know.

Keep everyone informed

Ensure this key member of staff talks to all staff members and finds an efficient way of keeping everyone informed.

Privacy

Be aware that some families will never want the fact that their child is going to die made public, so discussion will have to be about how ill the pupil is instead.

Explain

If you have permission to share the fact that the pupil is likely to die, explain to other pupils that treatment is no longer working and that the pupil with a brain tumour may die but that the most important thing for them is to have as normal a life as possible so they may visit school and keep in contact with friends.

Staff discussion

Make arrangements for staff discussion about the death or potential of death so that they can prepare themselves before telling pupils.

Inform staff

After the death, make sure all staff know that the pupil has died.

Establish support

Establish who is available to support staff and other pupils – do outside agencies need to be involved?

Acknowledgement

Acknowledge that the death may bring up deep feelings for some members of staff and if so, ensure they have support and do not have to be the nominated member of staff to help support the pupil. It is important for the school community to acknowledge the death of a pupil in a way that conveys the importance of each individual in the community and respects the child and the family.

Prepare a letter

A letter home to parents of other pupils will enable them to support their children in line with school – if the family agrees to this.

Sending condolences

Think about the best way to send condolences from school staff and pupils. It can be better to send a card or letter as well as telephoning, as these cards are tactile reminders of how important their child was.

Response

Consider how the school will respond about attending funerals or remembrance services.

Sibling behaviour

Consider siblings and how they may feel and behave.

Private space

Provide a private space for those needing to be on their own – for staff and pupils.

Group discussions

Tell pupils in small groups, using words like ‘death’, ‘dying’ and ‘dead’ rather than ‘passed away’ or ‘gone to sleep’.

Sharing

Enable pupils to share their feelings and have a place to go if they need to talk about the death.

Delayed reactions

Be prepared for a wide variety of responses: some pupils will have delayed reactions of a year or more later.

Repeat

Younger children will need short and repeated discussions.

Full information on this topic is available in Returning to School – A Teachers’ guide for pupils with brain tumours, during and after treatment 2nd edition (2014) by Dr Lesley Edwards, Dr Lynley Marshall and Gabriella Haemms of the Royal Marsden NHS Foundation Trust in collaboration with Cerebra.