St. Richard's Hospice

Supporting people with Autistic Spectrum Conditions before and after bereavement

Many people struggle to discuss death, dying and bereavement. It's a complex and emotive topic.

People with Autistic Spectrum Conditions experience the world differently to neuro-typical people, and tend to experience bereavement differently too. It is important they are offered the same opportunities to access emotional support from St Richard's Hospice as neuro-typical people.

Why is it important?

Evidence, research and data tells us people with Autism tend to:

- Like structure
- Rely on persistent sameness
- Have difficulty interacting and interpreting social cues
- Often have a desire to be alone

These tendencies are challenged both before and after bereavement.

What is important to people with Autism when communicating?

- Being able to control and predict their environment
- Knowing what's going on
- Knowing what's going to happen
- Consistency



How should we talk about death and dying?

Research and lived experience tell us people with Autism may struggle to understand euphemisms or language that cannot be taken literally. We need to make the implicit explicit, and it is best to avoid phrases such as:

- Passed away
- Gone to a better place
- Gone to sleep
- Lost

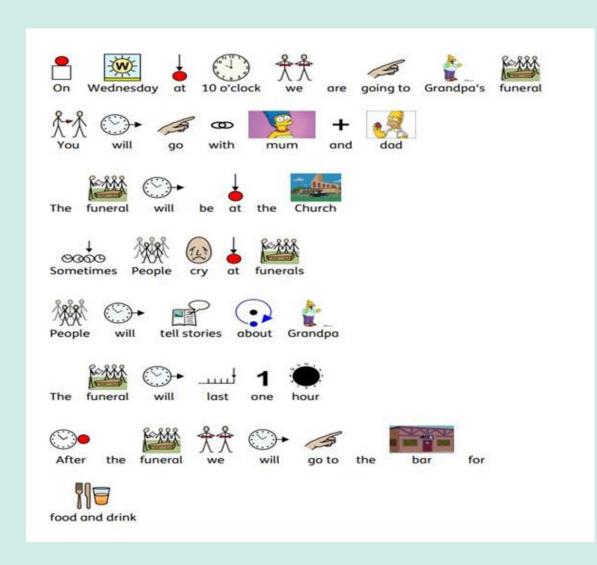
We don't shy away from using explicit language to remove any doubt about what has happened, such as:

"...has died" "...is dead"

An explicit message can be delivered compassionately, at the right pace, with the right tone, and with empathy and compassion.

How can we help with difficult social situations, like funerals?

Social stories, similar to the one pictured, have proved effective for many people with Autism. A social story is a short, scheduled explanation of an event or day.



If a person constantly needs reassurance, social stories are useful because they are consistent and can be referred to time and time again.

This can be a source of reassurance at an anxious or upsetting time.

How can we encourage people with Autism to engage in support?

People with Autism often have a very strong, idiosyncratic, focus of attention. It can be a good idea to establish areas of interest to stimulate engagement and understanding.



The social story pictured was designed for a boy who loved Star Wars. We supported him when his grandmother - who was cared for by St Richard's - was coming to the end of her life. The social story supported him to understand the process of

life, death, and dying. His parents stated he responded well to her death and had a greater understanding of death and dying.

What our families think

"We can never thank
St Richard's or Andy Schwab
enough for their support, and
we will be forever thankful that
Andy had the background with
Autism to help Brett* through a
very difficult time, as people on
the spectrum do not deal with
grief in completely the same
way as others."

*Name changed for confidentiality reasons



Andy Schwab, Specialist Palliative Care Social Worker at St Richard's Hospice aschwab@strichards.org.uk

Conclusion: At St Richard's, we treat every person as an individual. We are committed to ensuring anyone with an Autistic Spectrum Condition – or similar conditions – can access bespoke, client-led, specialist support.

We also offer free training on supporting people with Autism to local schools and care providers. We believe inclusive pre and post bereavement support can be delivered by other professionals with our guidance.

This way, we can do everything possible to meet the needs of people with Autistic Spectrum Conditions, and help them learn to live with their bereavement.

