

‘Peaceful, Pain free and Dignified’

Reflections on Palliative and End of Life Care

Jill Ferguson

... with the help and insights of the friends, family and support staff of
Stephane



‘Stories give us a deeper insight
into lived experience- past,
present and imagined futures’

IRISS Insights 23: the role of storytelling in practice

As we explore the individual narratives and life trajectories of the people we know and support, their experiences will influence and help shape current and future support.





Stephane

There was a change in Stéphane as the end approached. He became increasingly thin and withdrawn and we became very aware of the changes in his breathing. As his illness progressed some of the earlier challenges of his autism disappeared. He became a backrest and he became accepting of all the care and support that we provided. That was very different to what we had seen earlier in his life.

Valere
Manager

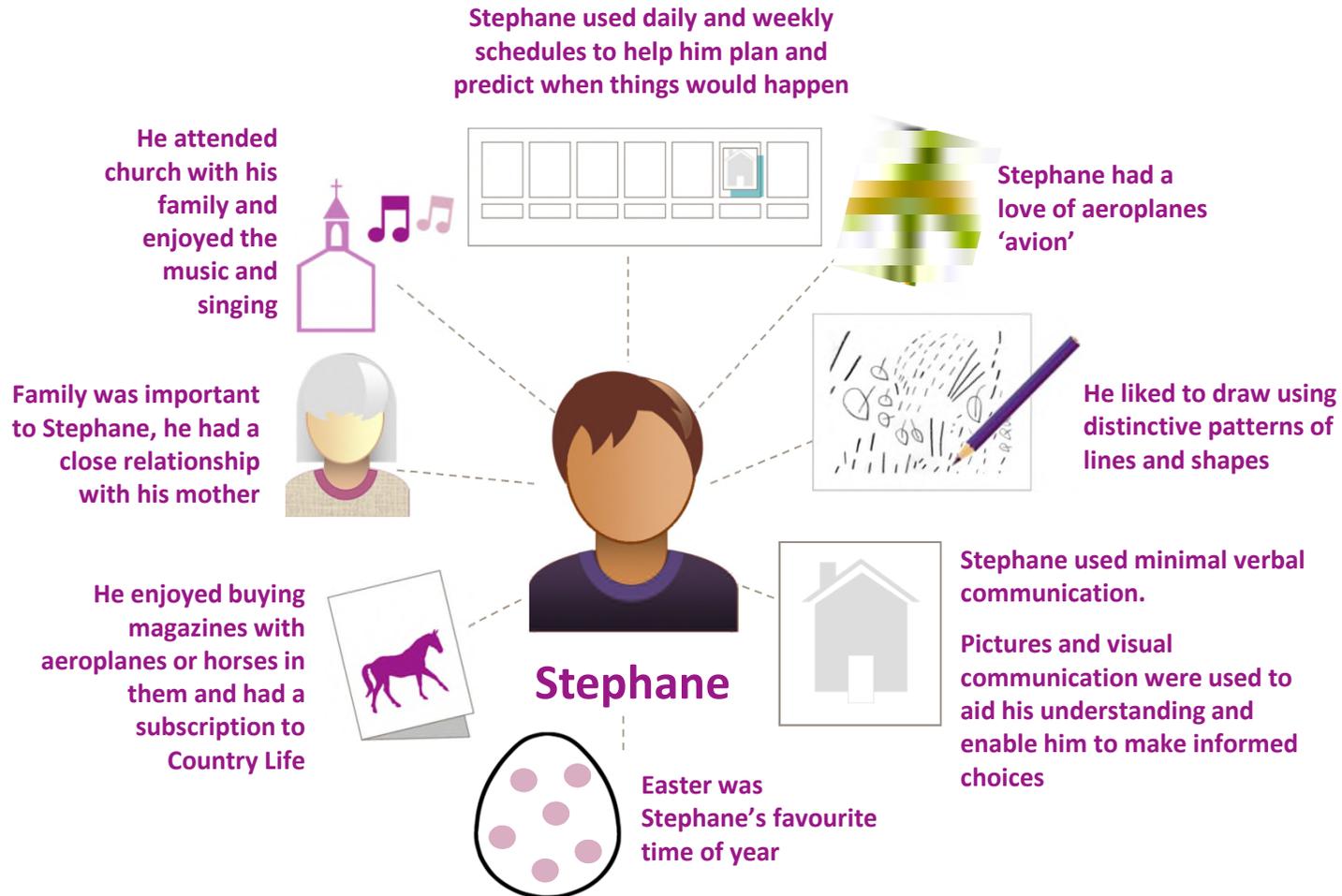
We spoke to the team before Stéphane died about the various ways it might happen. We spoke through the possible eventualities and what to expect at end of life. It was important to prepare them for what to expect.

Would I be able to deal with a dead body, that was something I didn't think about. But I did, because it was still Stéphane. Even after his death, I still had to care for him. I had to make sure he was presentable. These were things I could do myself. It was different now he's dead. If you really care for someone, you want to be somewhere to do those things that would be important to them.

Kitty
Keyworker

Peaceful, pain free and dignified:
palliative and end of life care for people on the autism spectrum
A guide for social care practitioners
All Freeman and Val Lurie

bid Scottish autism



Palliative and End of Life Care

Meet the team...



Autism Support Team– care staff



Palliative and End of Life Care Stephane's Story

Scottish
autism



Palliative and End of Life Care

Physical

Support Environments

Home-Hospital-Hospice

Requirement for
specialist care

Pain management and
medication

Diagnosis and Prognosis

Treatment planning

**Advanced Care
Planning**

Identifying and managing
symptoms



Palliative and End of Life Care Physical

Scottish
autism

Palliative and End of Life Care
Physical

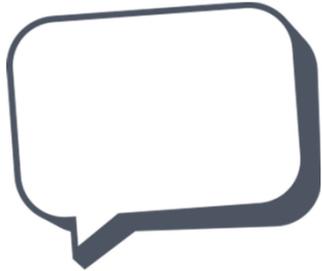
Scottish
autism

Physical



Palliative and End of Life Care

Physical



Discussion Points for Support Teams

What are some of the challenges identifying and communicating symptoms of ill health for the autistic adults you know and support?

Consider the person's ability to consent to medical treatment and interventions. Are there any issues of capacity or barriers to self advocacy that require support and consideration?

Care at home or Hospice. What kind of issues might have to be considered? What supports would be required to enable someone to stay in their home or transition to a hospice or hospital?



Palliative and End of Life Care Psychological

Understanding illness and prognosis

Loss of wellbeing

Minimising stress

**Creating positive
end of life experiences**

Identifying responses such as

**anxiety, fear,
depression, anger**

Psychological impact of

dependency



Palliative and End of Life Care Psychological

Scottish
autism

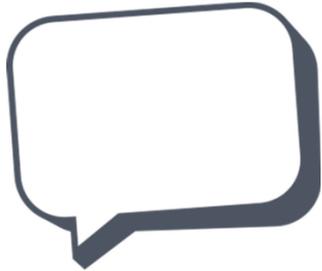
Palliative and End of Life Care
Psychological

Scottish
autism

Psychological

Medical
Social
Spiritual
Emotional





Discussion Points for Support Teams

How do the autistic adults you know or support express feelings of; **fear, depression, anger**? Are they able to label or articulate those feelings?

How would you best inform that person about their illness and prognosis?

What might the impact be of a significant loss of self ability for the people you know or support?



Palliative and End of Life Care Social

Preventing the **loss of social support networks**

Possible conflict between social needs and wishes of individual and those of key individuals in social circle

Peer support
Family support
Staff support

Reflecting on shared experiences

Re-defining roles and relationships

Social scripts and stories



Palliative and End of Life Care Social

Scottish
autism

Palliative and End of Life Care
Social

Scottish
autism

Social

Physical Psychological
Spiritual Emotional





Discussion Points for Support Teams

People are often fearful of discussing/ communicating issues of end of life care with the autistic adults they support and their families. What would you find personally challenging and why?

How perceptive is the person you know and support to the emotional and stress responses of others around them?

People diagnosed with a life limiting illness are often highlighted as being at risk of becoming socially isolated as their illness progresses. How might you support people to maintain important relationships. Might the social expectations of family and friends differ to the person you support?



Palliative and End of Life Care Spiritual

Scottish
autism

Cultural customs and beliefs

Religious
needs and wishes

Prevalence of spiritual
discussion and viewpoints
when dealing with issues
of death

Sources of **hope** and **personal inspiration**

Sense of past, present
and future

Selfhood

Giving experiences
meaning and
significance



Palliative and End of Life Care Spiritual

Scottish
autism

Palliative and End of Life Care
Spiritual

Scottish
autism

Spiritual
Social

Spiritual
Social
Family
Care



Palliative and End of Life Care

Spiritual



Discussion Points for Support Teams

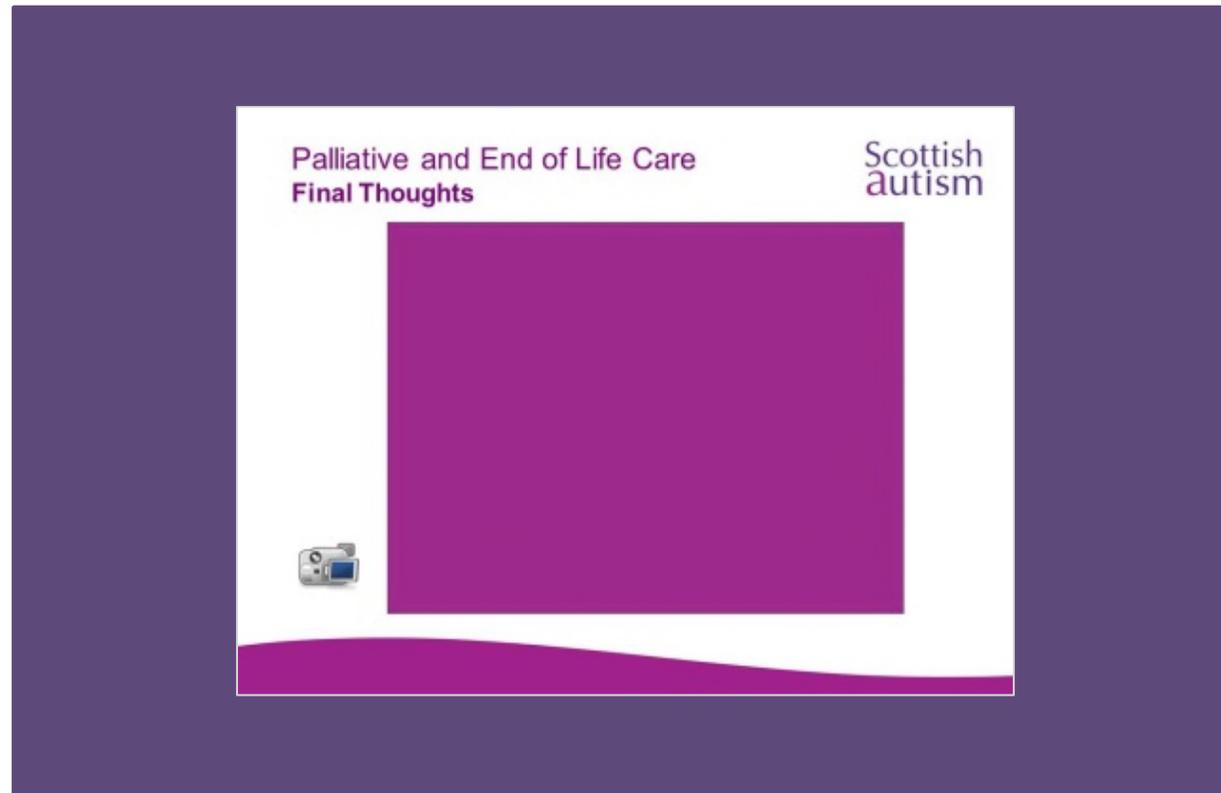
Spiritual themes and ideas often involve quite abstract and difficult to explain concepts. How do we provide meaningful explanations for concepts that we find difficult to explain ourselves- for example heaven.

Stephane's end of life care opened up a dialogue about death and illness with some of the autistic adults he had known throughout his life. How can we take difficult experiences and facilitate opportunities for learning and discussion with the people we know and support?



Palliative and End of Life Care Final Thoughts

Scottish
autism



Palliative and End of Life Care Founders House

Scottish
autism

Creating Support Services that are **fit for the future**



The Scottish Government's national action plan for palliative and end of life care called for a **person-centred approach** to palliative care

“...which recognises the diversity of life circumstances of people who will need palliative and end of life care”

Living and Dying Well

