

‘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.



Stéphane

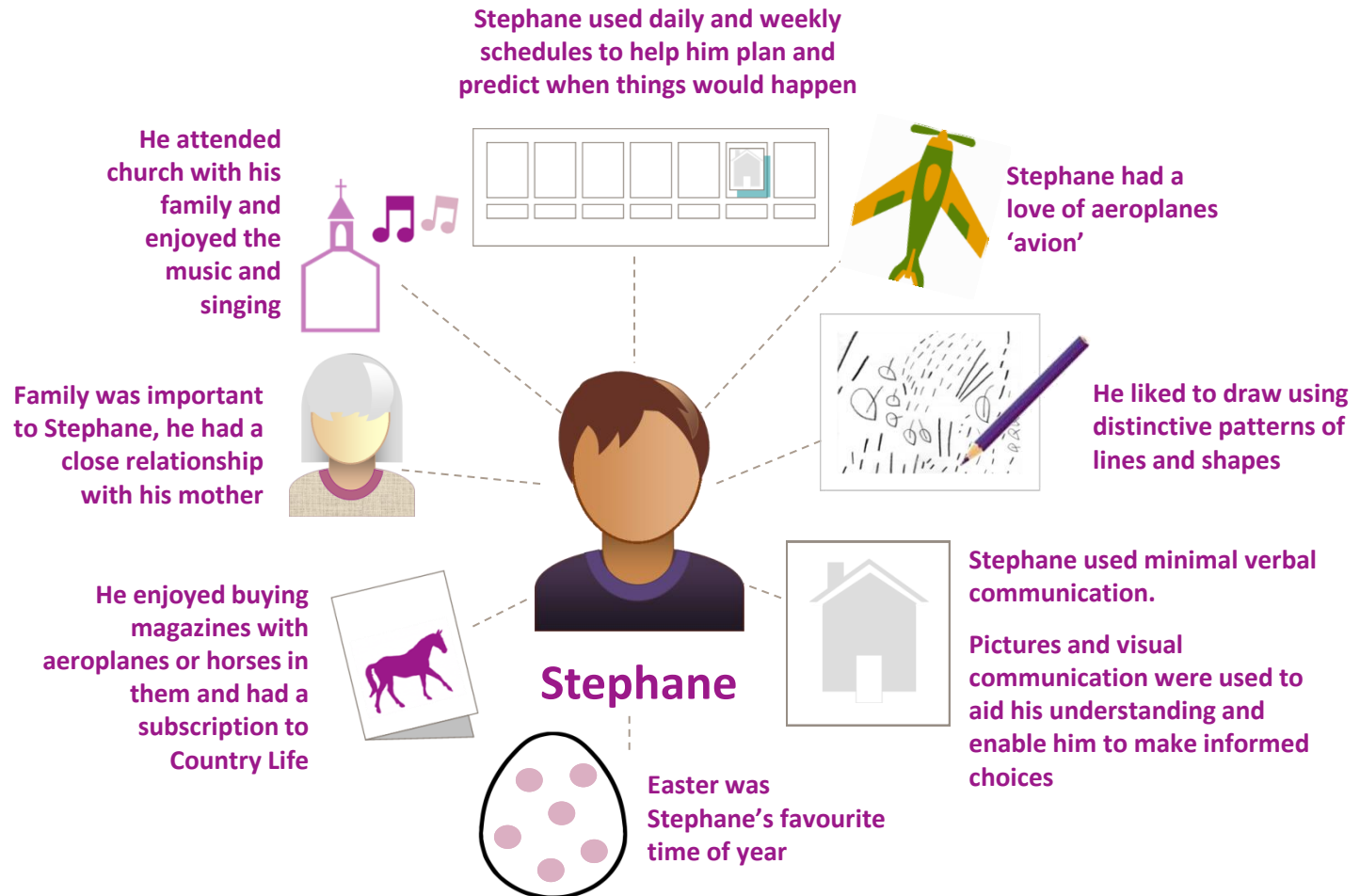
There was a change in Stéphane as the end approached. He became increasingly thin and withdrawn and we became very aware of the changes in his breathing. As his illness progressed some of the earlier challenges of his autism became more apparent. He became a back seat and he became accepting of all the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

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 he died, I had to be in to verify the death, we still had to care for him. It was a very presentable. These were things I could do with. It was a different now he's dead. If you really care for someone, you want to be somewhere to do those things that work.

Peaceful, pain free and dignified:
palliative and end of life care for people on the autism spectrum
A guide for social care practitioners
Jill Ferguson and Val Laurie

bild 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



Physical

Discussion Points for Care Teams

What are some of the challenges identifying and communicating symptoms of illness in the individuals on the autism spectrum you know and support? What implications might this have for diagnosis and treatment?

Consider the ability to consent to medical treatment and interventions for the individuals with autism you know and support? 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 the individual with autism you know or support to stay in their home? What support would be required in the event of a hospital or hospice admission?

Palliative and End of Life Care Psychological

Scottish
autism

Understanding illness and prognosis

Psychological impact of
loss of wellbeing

Minimising stress

Creating positive
end of life experiences

Identifying responses such as
**anxiety, fear,
depression, anger**

Psychological impact of
dependency



Psychological

Discussion Points for Care Teams

How do the people on the autism spectrum you know/ support express feelings of; **fear, depression, anger**. Are they able to label and articulate those feelings?

How would you best inform a person on the autism spectrum you know or support about their illness/ prognosis? Consider explanations and strategies to support understanding and promote emotional wellbeing.

What might the psychological impact be on the people you know or support following a significant loss of self ability? How would you counter negative feelings arising from an increased dependency on others?

Palliative and End of Life Care Social

Scottish
autism

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



Social

Discussion Points for Care Teams

People are often fearful about communicating issues of end of life care with the individuals on the autism spectrum they know and support, their families, friends and peers. What aspects would you personally find challenging and why?

How perceptive is the person on the autism spectrum you know/ support to the emotional and stress responses of those 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 would you support the people on the autism spectrum you know/ support to maintain important relationships? Might the social expectations of family and friends differ to those of the person with autism?

Cultural customs and beliefs

Religious needs and wishes

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

Sense of past, present
and future

Selfhood

Giving experiences

meaning and
significance

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



Spiritual

Discussion Points for Care Teams

Spiritual themes and ideas often involve quite abstract and difficult to explain concepts. How do we provide literal or meaningful explanations for things that we ourselves find difficult to explain?

For example: **Heaven**

How would you describe your thoughts on what heaven is to a friend?

How would you describe heaven to a person on the autism spectrum you know/ support?

Stephane's end of life care opened up a dialogue about death and illness with some of his peers. How can we take difficult experiences and facilitate opportunities for learning and discussions with the people on the autism spectrum you know/support?

Discuss:

Peaceful, pain free and dignified: a good death

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

