

Good morning and may I extend a very warm welcome to all of you here today at Holy Cross Hospital.

People have travelled from far and wide – from Houston Texas, from two Cambridge's (one in Massachusetts and one in England); from Oxford; Dublin and Belfast on the island of Ireland, Cardiff in Wales, from Spain, from the north east of England, the midlands, from London, Liverpool and Surrey and also from Liege in Belgium.

Holy Cross is one of a number of charitable works run by a religious order of Sisters known as the Daughters of the Cross of Liege, founded in 1833 in Belgium. When we moved to Haslemere in 1917 it was to run a TB sanatorium.

For many years we were a cottage hospital, but in the mid-80s, at a time when cottage hospitals were not the flavour of the month, Haslemere found itself to have two! This is how we came to transition across to neuro-disability, by identifying a need which wasn't being adequately met nearby ...and of course, with the likelihood in the background that the hospital would have to close if we didn't change.

I am pleased to say that one of our modern day Sisters, Sr Agnes, who was previously a matron of the Hospital, should be joining us in the early afternoon.

I should introduce myself. I am Ross White and I joined Holy Cross as CEO in February this year having been in the faster-stream rehab world beforehand. I was running a hospital in London working with patients who had neuro-cognitive impairment caused through HIV infection, a dementia-like condition, which in most cases was reversible with the right treatment and rehab programmes.

In the field of acquired brain injury and prolonged disorders of consciousness, I am struck by how much is now understood and yet how much there is still to understand and determine!.....

When I came flying out of a pair of skis three years ago and landed on my collar bone, the doctor told me that the fracture would be very painful for one week (it was) and much less painful after (true, although I did swear at someone who bumped into me getting off a bus in week-two), that I would be deeply bruised around the injury and that the bruise would spread out (I had a very colourful chest), and that in six weeks' time there was a 90-95% chance that the bone would have healed if I wore the support he gave t me. It healed. But if I had landed on my head, the doctor would not have been able to have had a conversation with anything like same degree of certainty. The error bars in our field can be large!

It is into this uncertainty, and with patients who can't easily communicate or who can't communicate at all, that we have to make best interest judgements for their care.

It's inconceivable that we would not wish to put together the best possible team for such a meeting - but yesterday we heard from our discussions that friends can bring different perspective to families, that men might take a different slant to women, or that family feelings about their own situation might not get totally disaggregated from the interests for the patient.

At a recent funeral of a patient here, a women in her late 30s, who had something similar to locked in syndrome, we heard how as a teenager she would climb out of the bedroom window to go clubbing. She would bunk off school at any opportunity. She never stuck at a job, getting bored and preferring to go shopping. Having been spotted walking down a street, she had been registered

with a model agency as a catwalk model, meeting exciting people on location and living the high life.

But after the funeral – the father said of her daughter’s death (which occurred three years after a major stroke)...’she would never have wanted to be this way, so this end really is a release’. Mum said...’I really miss her, she was very happy at Holy Cross’....I couldn’t disagree with either statement, and although not completely mutually exclusive, they very much took different views of the same situation.

I used to be Director of the Anne Frank Trust. You will know that Anne was a victim of the holocaust who for two years and one month was hiding in a few rooms in Amsterdam with her father Otto who she was very close to, her mother sister and four other people. It was close proximity every day for that length of time. She kept a diary which spanned the entire period.

Only Anne’s father Otto and Anne’s diary survived the war, and when he finally got to read her words he was totally shocked...saying ‘I just didn’t know my own daughter until I read what she wrote her diary’. This is perhaps food for thought for our loved ones who haven’t expressed their advanced directive wishes.

Prolonging life for people who would have not wished it to have continued, and withdrawing treatment for people who want to hang onto life, are very real issues for our field.

And in this field I really believe there is much more to consider in respect of research and technology - in recent years we have read about f-MRIs studies which have demonstrated cognition for some patients where other assessment tools would have yielded a different conclusion. But this is just one technology – and there is much more to be explored.

I sometimes wonder why we are going to Mars, when actually we might gain a greater ultimate benefit to humankind by exploring the brain. Perhaps there would be no greater endeavour than this?

That is one of the reasons why days like today are so important. It's an opportunity to share the latest research, to discuss the difficult issues, to agree frameworks which safeguard the best interests of those we have the privilege of caring for, to network and become friends as well as colleagues, and look to the future.

And that's why I am so grateful that you are here today.

Ross White, CEO Holy Cross. r.white@holycross.org.uk

Ross started has a scientific background with PhD research in magnetic resonance and neutron physics. Following nearly four years post-doc research in the French Alps, Ross completed an MBA and moved into charity management. He has held senior roles in the hospice movement, The Arts Council, the Anne Frank Trust, and Mildmay Hospital, before joining Holy Cross in early 2018.