

CHAPLAINCY AND SPIRITUAL CARE IN A CHILDREN'S HOSPICE

Kay Gilchrist

Kay Gilchrist, chaplain at Scotland's children's hospice, Rachel House, gives us a frank and personal insight into chaplaincy and spiritual care in this specialised field and setting. Reflecting on the atmosphere in the hospice, her own personal gifts, experiences and development, and the different needs of patients and their families, we are given a unique look into this special place and experience. Holding to a traditional understanding of faith in the face of the challenging questions of children is not easy. We discover each child needs an individual response, and often one that is personal and innovative

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"I only need to use this 'chair' for my physical body, my spirit is free so I'm as normal as any other boy my age."

That was said to me during a conversation with one of the teenage boys who uses Rachel House and due to his illness needs a power chair to get around. I felt it was quite a profound, confident and brave thing to say, especially with the knowledge that his life will be limited.

The chaplain's appointment

Rachel House in Kinross is the only children's Hospice in Scotland at the moment. It covers the whole of Scotland and aims to offer care to children who have a life-threatening, life-limiting illness, and their families, both at the hospice and at home. I have been Chaplain here for two years now. For the first year and a half I was part-time and since last summer I have been employed in a full time capacity. My work load/role I would imagine is much the same as any Hospital or Hospice Chaplain with the exception - maybe - that I visit at home, at the families request, and conduct more funerals. I also have the added pleasure to go on 'outings' with the children and their families that are ideal opportunities for me really to get to know them. I think it is fair to say that although I was delighted when I was appointed to the post, the appointment did bring with it a certain amount of fear, anxiety and trepidation - did God really know what he was doing?

The setting and atmosphere

I expect most people when they hear the word *hospice* think of death and dying and people lying in beds surrounded by friends and relatives waiting for the 'moment' to arrive. Although I was a bit more clued up than that, I still didn't quite know what to expect, especially with it being children. I'm glad to report I was pleasantly surprised.

Rachel House is a place that is full of fun, laughter, and maybe more importantly, full of life! Yes, there are sad times, there are times when you can feel absolutely useless, as though you have been no help at all. But on the whole the children and families who come here will tell you that they come here to live, and they live their lives to the full.

The Hospice is staffed by a multiprofessional team of people who work together to try and ensure that the children and families they care for are treated with dignity, respect and love, which will hopefully enhance and develop their quality of life.

Personal gifts, experience and development

It was into this team that I came offering my skills and experience of life, love, children and palliative care within the boundaries of my own personal faith and understanding of spiritual care. It has been well documented, and I think universally agreed, that

there is no one definition of spiritual care, and I am sure all of you reading this will have your own thoughts on that. My own understanding of spiritual care has certainly developed in my time here, and my interaction with parents around the 'meaning of life' has often originated in the most bizarre ways - playing pool, talking about football, discussing TV soaps, snowball fights!, creative activities etc. All this leads to building relationships and gaining trust, but, maybe more importantly, people come to know me not only as the Chaplain or someone who is going to 'talk religion' all the time (as many lay people think we do) but as Kay, a person. It's my belief that if I can approach a situation with a non judgmental attitude, and meet families where *they are* in their lives - not where I think they should be - and journey alongside them, then hopefully I am contributing to the holistic care which we strive to offer. By doing so I believe that spiritual care within the context of palliative care is not merely an 'appendage' but an integral part and vital to that care.

Working with families

Having been here two years I know many of the families quite well and have built up a rapport with them. It has also been very helpful to meet families in their own home environment. On a few occasions now I have been invited to the family home to discuss 'arrangements' for the funeral when the time arises. Parents can often feel very apprehensive asking me to do this. They are concerned that people may think they are being morbid and that they have given up hope. I would argue that they are being very brave, courageous, positive, loving and caring. If they strive to give their child the best care in life when he/she is alive, why not in death? If we believe that death is part of life then surely it is the natural thing to do. Also it is my experience that by discussing emotional, spiritual and practical situations whilst feeling relatively 'safe', parents and families can see a diminishing of the "regrets", "if only's" and "I wish I had" kind of thoughts and feelings in bereavement, which very often can block their 'healing'. Also when the death occurs, it gives them more time to concentrate on themselves and their emotions rather than have to think about what to do next!

Focusing on the individual

In all of this, where possible, the child concerned is very much involved in his/her own care. I have had many conversations with young people who don't 'hang back' from asking important and searching questions which has tested my faith to the full. A few examples:

Youngster: *"Kay can I give you a makeover?"*

Kay: *"It'll do no good, I'm past saving!"*

During the makeover - which I might add was at 11.30pm - she asked very leading and relevant questions such as - *"Kay do you believe in heaven? What's it like? Why do you believe in heaven? Does everyone go there?"*

Youngster: *"Kay will you help bath me this morning"*

Kay: *"Of course, as long as you promise not to splash me"*

During the bathing time the youngster asked me to tell her about the birth of Jesus in my own words. She then asked me to sing some choruses (bad move). She then went on to give me her experiences of 'church' at school, what she remembered of that time, and how come if we are told so many great stories of Jesus and what He can do, and how much He loves us, how come she doesn't feel it and He has never told her He loved her.

Youngster: *"Kay I believe in heaven and I believe in God. I'm not frightened, but I think my mum is and my wee sister. Why should my mum be frightened when I'm not?"*

Kay: *"I'll get you a juice and I'll get a coffee!!!"*

We then went on to have a really meaningful conversation, and it turned out that this young boy was hanging on to life until he was sure his mum would be okay. I had a conversation with his mum.

Youngster: *"I don't blame God for any of this, it's just something that happened"*

Kay: *"Cool, you've just made my day".*

All of the above dialogues happened more or less as written and I have developed my skills at reading between the lines and hearing what's not being said. With each youngster I approached the situation differently. I had to. Each child has to be treated as an individual. Spiritual care - in my understanding -

has to be offered on a person-centred level. It cannot be generalised.

Caring for those with profound needs

This sounds all very well for the children who can communicate intellectually and verbally. We have a number of children who are profoundly physically and mentally impaired, who can communicate in their own way, but are incapable of having any form of verbal conversation. I wasn't quite sure how I could provide spiritual care in these circumstances other than tactile loving hugs and touch, (which are very important,) but how could I strive to allay fears especially of death? There may be an argument that says that if the child is so profoundly mentally impaired, there is nothing for them to fear because they don't understand fear. My argument would be 'how do we know?' If they can communicate when they are in physical pain or distress then there is a possibility that they may just be aware of other things going on around them. To this end I have had many beautiful times with these children, especially at bed time, telling them stories, sharing my beliefs in a childlike fashion in the hope that they understand something. Also I believe that if I can help allay fears, doubts and anxieties of the parents of these children then that can only be of benefit to the child as their parents care for them.

Spiritual Care is a team effort

I was asked to reflect upon my time here at Rachel House and offer an insight into my role. I am aware that I have spoken about spiritual care in relation only to my role as chaplain. I acknowledge though, that all members of the care team play a large part in assessing and meeting the spiritual needs of the families who come here, and I have a part to play in the ongoing training and support of the staff as they

do so. I have been very much accepted by the team and I feel very much a 'part' of that team.

Questions and answers?

Although spiritual care may or may not be set in a religious framework, I feel that healthcare chaplains have a lot of work and educating to do to deliver this fact as many other professionals and laity still believe spirituality = God = chaplain!

I certainly don't have all the answers - and I don't believe I, or anyone ever will - to the questions that surround spirituality and the meaning of life. It has been my experience here that in order to offer the best care I can, theological dogma has to be left at the front door when I come in. When in a difficult situation and I'm not quite sure what to do my guiding light and port of call is to ask myself the question 'what would Jesus do?' My answer then is simple and I implement it the best way I can - with love. If I can continue to do that then I hope there will be many more young people who can repeat the quote from the young boy at the start of this article. "*I only need to use this 'chair' for my physical body, my spirit is free, so I'm as normal as any other boy my age.*"

Let me leave you with a thought from Virginia Satir, it helps me keep life and chaplaincy in perspective: '*Life is not the way it's supposed to be, it's the way it is. The way you cope with it is what makes the difference*'

References

SATIR V. (Reference unknown)

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