

The Pastoral and Spiritual Care of Young People with Neuromuscular Disorders – Facing the Questions.

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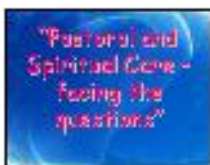
Conference Theme: Preparing for an Adult Life with a Neuromuscular Disease

Friday 19th May. 9.40 – 10.10am

ABSTRACT

Thirteen years of Chaplaincy amongst young people with neuromuscular disorders has raised some difficult questions for our speaker. The answers never seem to come in easily prescribed phrases or slick one-liners. Instead the response seems to come in disengaging from the moral laziness of being busy, and learning to “be there”, to be a presence. As relationships of trust form, mutual value is found, and hope is born. Perhaps this is the heart of spiritual care. However, everyone’s spiritual exploration and journey are unique. While it sometimes proves the highest understanding not to understand what life is like for someone else, there is something deeply human about sharing the journey.

Introduction



(PowerPoint) Well *god morgen* everyone and may I say how delighted I am to have been asked to speak to you and so, thank you, for the invitation.

Now I’ve just come across the top Franco-Belgian-Danish joke, which is as follows:



(PowerPoint) A dog goes into a Post Office and says to the clerk that he wants to send a telegram. So the lady says, “*what do you want to say*”, and the dog takes a blank form, and writes: “*Woof. Woof. Woof. Woof.*”

Woof. Woof. Woof.”

The clerk then says to the dog: "*There are only seven words here. You could send another woof for the same price*". "But", the dog replies, "*that wouldn't make any sense*".

Which tells us first that the Danish have a great sense of humour but it also reminds me that I have space for just 30 minutes and in that time my task is to try to make sense of Pastoral and Spiritual Care and how to face the questions.



(PowerPoint) "*Pastoral and Spiritual Care – facing the questions*".

You know, it seems to me that as the years go by I sometimes feel that I know less and less. I mean, faced with a talk like this, on a subject that's close to my heart, it's surprisingly difficult to articulate what you think you might know. And there's a bit of me that feels that much of what I want to say goes beyond words. Maybe I should just put on a piece of music.

Recently I led a memorial service for a young teenager who had died, (he had Duchenne Muscular Dystrophy) and all his mates wanted me to play tracks from "*Slipknot*", "*Prodigy*", "*Disturbed*", "*Papa Roach*" and so on. Real gutsy stuff with a lot of "*Parent Advisory*" lyrics. We played them all of course! It just seemed more honest.

And I was very struck recently by some training on "*Living With Loss*" which had taken place in a children's hospice. And the speaker said: "*Look under your chair and you'll find a set of scripts for how to talk to a family who have lost their child*". And everyone got up and looked, and then everyone laughed as they realised that there was nothing there – there was no script!

And as a mother said to me once: "*There was nothing to say, and you said it. Thank you*". And maybe the boldest pastoral care we can ever give is simply to be alongside but saying little, recognising that it is not always possible to improve on silence.

Treloars



(PowerPoint) For the past 13 years I have been the full time Chaplain for the Treloar Trust in Alton in Hampshire in the South of England. Some of you may know that Treloars is a residential School and a College for young people with disabilities who come from many parts of the UK.



(PowerPoint) About 80% of our students are wheelchair users, some 30% have no speech and 10% have progressive conditions and particularly Duchenne Muscular Dystrophy. In England that compares with 1 in 10,000 children in our mainstream schools. So at Treloars we have created a fairly intensive environment for ourselves, although very much an environment of laughter and hope.

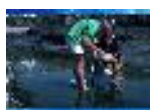


(PowerPoint) Treloars is a place where our students, and especially those who may face a poor prognosis, are enabled to live the *width* of their lives and not just the length and where hopefully they can add *life* to their years.



Although, looking at this picture you might wonder about our risk assessment policies!

(PowerPoint)



(PowerPoint) It's a fun place to be, where students are enabled to live creatively within their reality. And it's phenomenally well resourced, with nearly 800 staff for 320 young people.



(PowerPoint) It's been around for 100 years now and was founded by Sir William Purdie Treloar, a Mayor of London. although I like to think that things have moved on since those days!



(PowerPoint) whatever this was about.



(PowerPoint) and certainly the school uniform has improved!



(PowerPoint) But I guess our main vision is of a world where physically disabled young people learn to take control of their lives and dare to dream and where lives can grow and be celebrated.



(PowerPoint) The symbol of Treloars is a tree, and the fruits of our tree are always the students themselves who show that no one is of less value than others and no one is just an invalid.

The word “invalid”, of course, can be pronounced *in-valid*. It’s the same letters. But no one is in-valid in God’s sight.

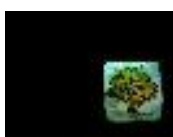
My Role



(PowerPoint) My role as Chaplain is simple really, because it’s about enabling these children and young people to discover that they are loved by their God, and valuable to him and somehow eternally significant and eternally safe.

It’s all about relationships, relationships that transform, and become a sign to everyone that all we welcome are important and that God never makes junk.

And in a real sense, actually, I work as a missionary. Which I know is not a very cool thing to say. But a missionary is not someone who crosses the sea, but one who sees the cross. And I see the cross every day.



(PowerPoint) Back in June of last year I sat with a young chap of 14 years old. Again he has Duchenne Muscular Dystrophy. He was about to have a spinal fusion operation up in Stanmore Hospital near London.

And having first shown me how skilled he was in getting a high score on his “X Box” computer game, he asked me to lift his arm up because it had fallen to one side. Then he told me that he was worried and said: “*When I die, one day, who is going to look after my mum?*”



(PowerPoint) Well I found myself thinking of Jesus on the cross, (sort of thing Chaplains do!), and I began to realise just where I was sat, because it reminded me of Christ, who had become, to all intents and purposes, a quadriplegic man. And as he hangs there, paralysed by the nails, disabled by this non-accidental injury and in respiratory failure, he worries about his mother.

And with extreme effort Christ managed to express his living will with the words: “*John, look after my mum*” – or at least words to that effect.

That young 14 year old was teaching me theology.

Chapel Window



(PowerPoint) Have a look at this. This is a picture of a window in our College Chapel. It was designed by a 17 year old, *again* with Muscular Dystrophy. His name is Stuart Reid. And it’s one of three windows.

He has absolutely minimal hand function. And to produce the work, which was part of his “A” level Art course, required extraordinary effort.



(PowerPoint) I commissioned a parent who makes stained glass to make them and the TV cameras captured his face the first time he saw the end product of his work. It was a real picture of incredible joy.

And I think his work tells us that there is so much mature reflection and insight going on in the minds of young people, more than we know, and especially with those facing progressive conditions.



(PowerPoint) And for Stuart it says: *“I was here. This is how I saw my world - look at it with me now and when I am gone.*

I made a difference”.

Deaths

During my time at Treloars some 38 students, current students, have died with Duchenne Muscular Dystrophy, and some 19 with other conditions.



(PowerPoint) I have taken most of these funerals in different places all over the country, and I have certainly led all of the Memorial Services.

And I was looking through some of the things I have said at these services about the students who have died. For example:



(PowerPoint) *A passion for cars, a love of nature, obsessed with heavy rock music, went abseiling in his wheelchair, canoeing, clubbing, an artist, photographer, skilled in IT, boozier, passion for girls, Scout, actor, poet, Manchester United supporter.*

And in describing how their personalities were always bigger than their disability, I have used words like,



(PowerPoint) *thoughtful, reflective, confident, enquiring, caring, independent, obnoxious teenager; no stranger to grief, compassionate, a pleasure to know, friend, gentle, tolerant, uncomplaining, happy, wicked sense of humour, complete pain in the neck!*

Losing such extraordinary people has left us with a commonwealth of woundedness. And I stress the word “wealth”, because



(PowerPoint) it is a privilege to know such amazing people not as patients, but as fellow human beings on the journey of living. And it means that we are never just spectators, we are always participants.



(PowerPoint) Skilled companionship runs deep, and while recognising our professional boundaries we are inevitably emotionally involved with our fellow human beings in need.

At times we are wounded carers ourselves, often faced with personal limitations and perhaps a sense of inadequacy in the face of the crushing unfairness of every day life.

We try to understand what it must be like to have a neuromuscular disorder, but it is never really possible to understand what it is like to be someone else, anyone else. And sometimes it proves the highest understanding not to understand.

Questions



(PowerPoint) Treloars is a place of questions. And whenever any of us spend time with people with neuromuscular disorders we are inevitably faced with questions.

Questions, as a Chaplain, are my bread and butter. In the oldest book of the Bible, the Book of Job, there are 288 question marks – many asked by Job, and some by his carers. But the answers God gives to all these questions about suffering come in the form of yet more questions: 78 of them in fact.

In the Gospels we have a record of some 248 questions asked by Jesus. The last one he asked as he died: “*Why have you forsaken me?*”

It's hard living with questions. They can leave us feeling unsure of ourselves. They can open up gaping holes in our thinking, in our theology and philosophy of life.



(PowerPoint) Recently I have been asked:

“Why am I disabled?” “Why am I here?” “What is heaven like?” “Is my little brother in Paradise now?” “Can I be cremated if I have had a spinal fusion?” “How do I pray?” “What is God like?” “Why is God so cruel? What did I ever do to him?”

When people face challenging life events such as serious illness there is often a fundamental spiritual crisis that questions their very existence.

Often they surface when there is little eye contact, perhaps at times of intimate care, such as bathing or hair dressing, or perhaps the questions surface in a car, when they don't have to look at the driver's face. Taxi drivers often get them.

Often we would prefer to avoid these difficult and deeply human questions.

Preferring to limit it all to what we might ask in a shop: *“Do you speak English?”* or *“Do you take VISA?”*

And in our place of work we want clear-cut policies that address every possible scenario. Easy answers. And I'm afraid it's often true in the church as well. People wanting black and white answers to the complex human story. *“This is right... that is wrong”*. Medical ethics reduced to simplistic solutions that often leave people out in the cold and pastorally abandoned.



(PowerPoint) I remember a man who once cut his finger.

And he thought it might need a stitch so he went to Casualty. When he got there he was faced with two doors. One said *“Cuts”* the other said *“Diseases”*. So he went through the *“Cuts”* door. At the end of a long corridor he was faced with two more doors. One said *“Thorax”*, the other said *“Limbs”*. Well he didn't know what *“Thorax”* meant and so he went through the *“Limbs”* door.

Eventually he was faced with two more doors. One said “*Major*” and the other said, “*Minor*”. And looking at his cut he thought to himself that it wasn’t a particular major cut, so he went through the “*Minor*” door and immediately found himself back outside in the car park!

His friend asked him whether the hospital had sorted him out, and he said: “*No! But they were sure well organised!*”



(PowerPoint) And sometimes we are so well organised, extremely and professionally busy, and yet miss that moment of human contact. That small voice from a child, who in asking us a question might awaken something in us, and the encounter could have become a holy moment.

And the hardest questions are often not medically related and often don’t have an answer. And if we think we have an answer for everything, then I suspect it shows we have not confronted the question.

Answers

So perhaps in the face of difficult questions there are no easy answers, just good responses.

But these are rarely cognitive verbal responses, or clever theological phrases.



(PowerPoint) The answers are often found in attentive listening, in not running away into our moral laziness of being frantically busy.

Attentive and non-judgemental listening. Attempting to understand their cultural or religious background or life experience, which may be vastly different from our own.

For the Christian culture, God does not give us easy answers, but he gives us his Son, who enters the heart of the questions.

And there lies our clue in what is perhaps our model for good pastoral and spiritual care. Because the Christian answer to suffering is rarely an explanation but a presence.

Presence



(PowerPoint) And the concept of presence is very often explored in Nursing literature as well as being a profoundly Christian concept.

Because “*being there*” for our fellows with neuromuscular disorders, whoever they are, whatever their appearance, youth sub-culture, race or creed, speaks volumes about self-worth. It says: “*You matter to me. You are worth my care, I am with you, and you are not alone*”.

Being truly present with someone confirms their uniqueness and carries with it unconditional acceptance. It gives them value.

And so you become their **companion** in what could otherwise be a very lonely journey.



(PowerPoint) The word *companion* comes from two Latin words: **(PowerPoint)** “*Com*” meaning “*with*” and “*Panis*” meaning “*bread*”; and so it literally means “*With bread*” or “*sharing bread*” - again,



(PowerPoint) a profoundly Christian idea, and perhaps the heart of what is meant by the sacrament of breaking the bread, *sharing the broken body*.

Relationship



(PowerPoint) And companionship speaks of relationship. And again, this is a key element in good pastoral and

spiritual care. But it is a relationship that can leave us feeling pretty vulnerable and exposed to other people's pain.



(PowerPoint) As Dr Sheila Cassidy puts it: *“Pain is part of the human condition and sharing that pain is a deeply human task”*.

And sharing ourselves, our common humanity, brings meaning into the situation.

Blessing & Meaning



(PowerPoint) I like the way that the words *“wound”* and *“blessing”* have the same Old English roots. And to find some kind of blessing in the middle of an otherwise *“neuro-illogical disorder”* is a breakthrough in our spiritual care.

Parents look for meaning. They are so often grieving and trying hard to work towards acceptance, which Professor Joan Bicknell defines as



(PowerPoint) *“the death of the imaginary child, and the redirection of parental love to the newly perceived child in reality”* - Prof BICKNELL, DJ., 1983. *The Psychopathology of Handicap*.

British Journal of Medical Psychology, 56, pp. 167 - 78.

In other words they grieve the child they had longed for and learn to love the one they find themselves with. But it can be a long and bumpy journey from resignation to reconciliation.

The disabled child may be growing up in a family of many tears and they may find it hard to believe that they are a source of joy, and a person to be celebrated.

But the blessing comes from these wounds when the parents discover that their child is leading them away from the world of power and competition into a world of tenderness and compassion.



(PowerPoint) Or as a mum of a young lad with Muscular Dystrophy said to me only the other day: *“What you think is valuable in life changes its goal posts when something like this happens to you. So many things become unimportant, while other things, new things, take over your whole life. We changed. In fact our faith changed. But if anything, it deepened”*. (Karen Blumire)



(PowerPoint) Her son was confirmed in church the other week and he said to me in his Confirmation Class: *“You know Ed, if I didn’t have this disability, I would not have found my faith”*.

Living with Loss



(PowerPoint) But living with and preparing for an adult life with a neuromuscular disease is often about living with loss.

At Treloars we have found that our young people show many of the symptoms of traditional grief. And very often the behaviour of the chronically ill adolescent needs to be seen in the context of grief. And good pastoral care will seek to understand this.

Grief begins long before the death, both in the life of the dying person and in the lives of their friends and family.



(PowerPoint) There is, of course, a grieving over the progressive **loss of mobility by walking**. An average person takes between 5,000 and 10,000 steps a day. So when we have been used to this it obviously comes as a huge loss not to be able to stand anymore. As one student told me: *“If I had only known that that was going to be the last day I was to walk, I would have walked and walked all day”*.

A very experienced colleague of mine was taken up short recently when a severely disabled teenager was chatting to her and began with the words: *“When I used to play mini-rugby ...”* And she didn’t hear the rest of what he said because she never imagined that he used to play rugby. It was a revelation.



(PowerPoint) Then there is grieving over the **loss of normality** as a young person. And good pastoral care will be aware of this.



(PowerPoint) Teenagers are a strange breed. As the car bumper sticker says: “*You can always tell a teenager, though you can’t tell them much!*”

Aristotle (384-322BC) said: “*When I consider the younger generation I despair for the future of civilisation*”.



(PowerPoint) But when you have a progressive neuromuscular disease it is really hard to be a *normal* teenager. It’s hard to slam the door and leg it to your mates if you need someone to open the door for you in the first place.

And young people who have faced a lifetime of chronic illness or disability may well have found it difficult to move on from the world of their childhood. They may not have had the opportunities to develop independence.



(PowerPoint) If a teenager becomes chronically ill their sense of belonging to their particular youth sub-culture may be jeopardised by the institutionalising of their illness. It’s hard to belong when you can’t go clubbing.



(PowerPoint) And with long-term sickness they may start to identify with us, **(PowerPoint)** to belong to us, the healthcare professionals.



(PowerPoint) Arriving in hospital or hospice, (which is unknown territory), means that the adolescent enters an adult led world, a world full of responsibilities, accountability and of adult concerns.



(PowerPoint) Whilst in this care the trappings and fashion uniforms of their sub-cultures - their music, access to cool shops, mobile phones, chat-lines, and their independence in relationships, may be stripped away. Piercings may be removed (perhaps for an MRI scan) and use of make up may be minimised, taking away their power to shock.

So consequently their important self-image is likely to be under threat by the illness and the effects of treatment. Separated from their social network, the adolescent may feel alone, scared and angry, finding it hard to relate in such a foreign land.



(PowerPoint) And self-image is everything. In the UK research has shown that (*Royal College of Nursing in 1997 questioned 4,295*).

86% of 11-16 year olds fretted about the way they look.

60% of 15 year old girls wanted to lose weight, and

78% of 17 year olds were unhappy with their bodies.

(*Quoted in The Times 1997*).

Also, in the UK 15% of 14-year-olds have considered cosmetic surgery.

Odds are the teenager in your care is *already* unhappy with the way they look, long before we start giving them complex surgery.

So with long term hospital admission the teenager can rapidly lose touch with their world of school, college and place of work. They may even have given up catching up with their peers and of fulfilling their ambitions. The enormity of grief that can develop should not be underestimated.

Again, a young chap I knew, who was such a wonderfully rebellious and talented teenager, but with Duchenne, once quietly said: “*I never planned my life to turn out like this, you know*”.



(PowerPoint) One of the predominant themes in adolescence is the feeling of immortality or being exempt

from death. Becoming chronically ill results in the **loss of such innocence**.

And when faced with the increasing implications of their condition, the adolescent will grieve in the same way as an adult, often following the common stages (although in no particular order) - shock/denial, anger/protest, bargaining, sadness, and resolution. - All healthy and normal reactions.

But the young person may also turn to destructive behaviour such as developing an eating disorder or some other form of self-harm. This might be an attempt to gain some kind of control.

They might also abuse alcohol or substances. After all, a landlord is just another pharmacist - only with a rather limited inventory!

Or as one student told me recently: *“I’d rather have a bottle in front of me than a full frontal lobotomy”!* - He’d just been done, incidentally, for being drunk-in-charge of a wheelchair!

Sexuality and conflicting emotions



(PowerPoint) Sexuality is often an important pastoral issue.

People with debilitating disease do not cease to have sexual needs, although it may change the way such issues are addressed.

Many teenagers are already sexually active and may have a fairly long-standing relationship. Some neuromuscular disorders, have the potential to negatively affect sexuality and their body image, diminish sexual functioning and feelings of attractiveness.



(PowerPoint) However, *“good sex is built on good communication not good bodies”*. (Monroe, 1998)

And good holistic care will acknowledge sexuality.

Obviously there are some big issues surrounding all of this and sadly there isn't the time to explore them now. Are they over 16? Are the parents aware? Are they on the Pill? Is there a girlfriend or boyfriend who should be respected as the most significant peer? Would it be appropriate for their friend to be present if and when the young person is dying?

Sometimes there may also be an increasingly desperate attempt to meet sexual longings and fantasies.

Cravings for touch and physical comfort are often intensified when facing the shock of illness. And sexual activity can also become a distraction from pain including spiritual pain.

And then sometimes the teenager who is exploring their sexuality may consider asking for sexual favours from adults around them including their carers. Obviously there are some very clear professional boundaries here.



(PowerPoint) But for me, the most worrying loss is the **loss of meaning**. And spiritual care is often about trying to make sense of your life when it is so dominated by a progressive disease. Trying to believe that there is an underlying meaning touching the whole of your life journey.

C.S.Lewis once said: *“If there is meaning in life at all, then there has to be meaning in suffering.”*

Dostoyevsky once said: *“The secret of man’s being is not to live but to have something to live for.”* Or as someone else put it: *“Better to die for something than of something”*.



(PowerPoint) Viktor Frankl, the Austrian psychiatrist, was fond of quoting Nietzsche: *“He who has a why to live can bear with almost any how”*.

So finding meaning helps us to cope. If the condition has some kind of meaning, however tentative, then we can be at peace.

But for some, meaning is found in unhelpful ways. In some cultures, for example, the disease and even the disabled children themselves, are seen as a punishment from God.



(PowerPoint) I remember meeting a parent. He was a successful businessman. He sat on the edge of his chair as he said to me: *“I believe that the reason why my son has muscular dystrophy is because when I was a child I stole some pennies from my grandfather. I am sure my stealing has a lot to do with it now.”*

He was an intelligent man – he just couldn’t make sense of his son’s suffering. In a way, he was looking to me for absolution. He was in spiritual pain.

My task was to listen to his story, to hear his questions about meaning in a non-judgemental manner and to try to provide significant presence for him, not to abandon him.

Spirituality



(PowerPoint) Perhaps *“The heart of spirituality is about the transcendence of one’s own self and the forming of deeply loving and compassionate relationships with others.”*
(Anthony Seldon, headmaster of Wellington College.)

So good spiritual care helps to promote a sense of well-being, of self-esteem, value, trust, hope, and meaning, which reduces that ghastly sense of isolation. And this, in turn, helps the patient to cope more happily.

Spirituality is a quality of life issue. In fact there is *“a growing awareness of the contribution that spiritual well-being can make to patients’ actual and perceived health and quality of life”*. (Brady et al, 1999; Chibnall et al, 2002; Mont, 2003).

There is certainly *“a growing body of evidence ... that spirituality enhances health.”* (Spirituality and Health. J. Coyle. Journal of Advanced Nursing March 2002. Vol. 37)

The trouble is there is no recognised definition of the word “spiritual”.

And with the increase in interest in eastern philosophies and complementary therapies the term “*spiritual*” is increasingly banded about.

I find it helpful to make a distinction between religious need and spiritual need. And while not everyone will have an obvious religious need, spiritual need is universal.



(PowerPoint)

Religious belief acts as a very significant support to those suffering a chronic disease, not only providing optimism but also a ‘fighting spirit’.

And we should not underestimate the many teenagers who have a religious affiliation these days, perhaps with a mosque, synagogue, church or thriving Christian youth group.



(PowerPoint) Religion is the ritual or liturgy we use to express and focus our spiritual beliefs. And this may include:

- Religious rites
- Prayer
- Sacraments
- Fasting
- Dietary requirements
- Code of ethics and so on

(Harrogate Health Care NHS Trust – Spiritual Care Policy)



(PowerPoint) But what do we mean by spirituality? One definition speaks of spirituality as “*a quality that goes beyond religious affiliation, that strives for inspirations, reverence, awe, meaning and purpose even in those who do not believe in any god.* (Cited in McSHERRY. 2000). Murray & Zentner (1988)



(PowerPoint) But in defining spiritual care I like the story of Adam and Eve in the Garden. Adam and Eve are hiding in the bushes and very aware of how vulnerable they’ve become. And God walks in and asks them a question. (As you do).

And he doesn't ask: "*What have you done?*" which is a judgemental question. Nor does he ask: "*What's the matter with you?*" which is about diagnosis.

But he asks: "*Adam, where are you?*". And it's that "*where are you, where are **you** in all of this?*" that I believe is the spiritual care question.

And I tend to start from the simple premise that all human beings are sacred, whatever their culture, race or religion, whatever their capacities or incapacities, whatever their weaknesses or strengths may be.



(PowerPoint) Or as Jean Vanier puts it "*Each of us has an instrument to bring to the vast orchestra of humanity, and each of us needs help to become all that we might be*". (Jean

Vanier- "*Becoming Human*" DLT.

This is not to deny the fact that some people are absolutely clear in their own mind that there is no God. They see their world in a totally secular way.

But again, non-religious people have the same needs for reassurance and emotional support as those who have access to the traditional "*comforts of religion*".

And whoever we are, whatever our beliefs, we all of us need attention, affirmation and affection.

And so if medicine involves the recovery and care of the body, spiritual care involves the recovery and care of the patient as a person. The two complement one another and remind us



(PowerPoint) "*There is no profit in curing the body if in the process we destroy the soul*". Anon.

And so spirituality is about being fully human and it shapes our lives and our humanity.

When we address the spiritual need of those in our care, we are looking for our common humanity, looking beyond the "*them and us*" and often this involves some kind of self-disclosure.

The trouble is we tend to view patients as somehow “*other*” than ourselves, and perhaps especially those with disabilities.

I know of a hospital chaplain, for example, who is a wheelchair user. And the doctors often find it hard to work with him because they somehow feel that people in wheelchairs must be patients and not colleagues.

So how do we identify spiritual need? Well, there is, of course, a vast amount of literature these days concerning our assessment of spiritual need and a wealth of guidance on understanding our provision of religious care for people with different faiths.

And I recommend the notes and the booklist I have given you for this.



(PowerPoint) But I especially recommend this site on the Internet if you need to know more. The Multi-Faith group for Healthcare Chaplaincy. They’ve done all the work for you!

Again, you will find useful checklists to **recognise spiritual need**, which are also in your handouts.

And I am grateful to the *Harrogate Health Care NHS Trust and their Spiritual Care Policy*.

If we want to identify spiritual pain or distress, then look out for the following:



(PowerPoint)

- Anger – Directed at God or other people.
- Bitterness – “*What have I done to deserve this?*”
- Regret – “*I should have been a better person.*”
- Guilt/punishment – “*I must have done something wrong.*”

(PowerPoint)

- Doubt – “*Is there a God, is there really a purpose for existence?*”
- Fear – “*I am not sure there is anything after death.*”
- Isolation – “*My family/friends/neighbours/God etc. have abandoned me.*”
- Loss of hope – “*I see no future*”

(PowerPoint)

- Tearfulness.
- Questioning/meaning of suffering/life/death.
- Nightmares/sleep disturbance.
- In denial.
- Withdrawn.

So how can we be sure that we are meeting spiritual need?

Here's a checklist of questions.



(PowerPoint)

- Are we “being there” for the patient, standing alongside them in their spiritual distress, available and approachable?
- Do we provide privacy, dignity, and a secure caring environment?
- Does the patient have good symptom control and a better opportunity to explore deeper issues?

(PowerPoint)

- Do we provide a listening ear to enable the expression of feelings of fear, anger etc?
- Are we giving reassurance about physical care and pain control?
- Do we show respect for patient's integrity, worth and values?
- Are we supporting the patient's family?

(PowerPoint)

- Do patients need help with “unfinished business”. Is there anything they need to do or say?
- Are we mindful that as physical health recedes, the spiritual dimension may grow in importance?
- Giving complete attention to a patient' is spiritual care.

Hope



(PowerPoint) Back in 1966 Clinebell gave us a framework of four spiritual needs:

1. The need for meaning and purpose in life
2. The need to give love
3. The need to receive love
4. The need for hope and creativity.

(Clinebell, H.J.: 'Basic Types of Pastoral Counselling: New Resources for Ministering to the Troubled' – Abingdon, New York. 1966.)



(PowerPoint) But the discovery of hope is perhaps the most precious element in our care. Because there is a close connection between hope and spiritual well being. In fact hope is so vital to life, that to lose it is like losing

life itself. *(Fromm 1968. 'The Revolution of Hope' Harper Row. New York.*

There is even evidence that in 'hoping for' a particular event, an individual can appear to be able to control the time at which they die. (*Kate Flemming. 'The Meaning of Hope to Palliative Care Cancer Patients'*)

And if we have the trust with a patient that can inspire hope we need to be aware that we also have the power to cause loss of hope, and so we have to have good pastoral skills in breaking bad news.

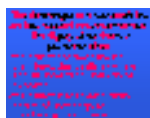


(PowerPoint)

Coming to the end

At some point our fellow human being may seek permission to die.

And this should not be seen as the relinquishing of all hope. There comes a time when death is no longer the worst thing that can happen on a spiritual journey.



(PowerPoint) But the final stages of a person's life are timeless and precious moments. And the dignity of the death is preserved when:

- **(PowerPoint)** The patient and those around them know that death is coming, and all understand what can be expected.
- **(PowerPoint)** The patient is enabled to retain control of what happens.
- **(PowerPoint)** The patient has control over pain and has symptom control for as possible.
- **(PowerPoint)** The patient has control over where the death is to take place, either at home, in hospital or in a hospice.
- **(PowerPoint)** The patient has perhaps been able to indicate who is to be present and who shares the ending.
- **(PowerPoint)** Any advance directives should have been explored which ensure that their wishes are sought and respected.
- **(PowerPoint)** There should be time to say goodbye, to leave when it is time to go.

All these are recognition of their uniqueness, and a respect for our common humanity, and so reflect good spiritual care.



(PowerPoint)

Conclusion

Well my time is done. But just by way of conclusion, I hope that what I have shared has improved on silence, but again, much of what I have tried to share, from my own experience, goes beyond words.



(PowerPoint) As far as developing our skills in pastoral and spiritual care are concerned I would encourage you to **appreciate the questions** we are asked, or that we ask ourselves.

Perhaps finding opportunities to ask them together with colleagues, and to explore them.

(PowerPoint) **Answers** come in the form of being there for one another, giving each other presence.

(PowerPoint) And out of this honest encounter comes **relationships of trust**, and our sense of **mutual value** begins to grow.

(PowerPoint) And from this, we find the ultimate prize, the gift of **hope**, which leads to well being.



(PowerPoint) Well, there is a lot of hope in this room, and it is a wonderful gift to share. Thank you for listening & bless you all.

Facing the Questions – is there time?

The Pastoral and Spiritual Care of Young People with Neuromuscular Disorders – Facing the Questions.

International Meeting in Paediatric Neuromuscular Rehabilitation
18-20 May 2006
Vingstedcentret, Denmark
Friday 19th May. 9.40 – 10.10am

Rev'd Canon Edward Pruen - Chaplain for the Treloar Trust,

Upper Froyle, Alton, Hampshire. GU34 4JX. UK. (0044) 1420 526400.
ed.pruen@treloar.org.uk www.treloar.org.uk

QUOTATIONS FROM THE LECTURE & ADDITIONAL NOTES

- And as a mother once said: *“There was nothing to say, and you said it. Thank you”*.
- It is not always possible to improve on silence.
- Enabled to live the *width* of their lives and not just the length and hopefully add *life* to their years.
- We share a commonwealth of woundedness.
- We are always participants – never just be spectators.
- In the oldest book of the Bible, the Book of Job, there are 288 question marks – many asked by Job, and some by his carers. But the answers God gives to all these questions about suffering come in the form of yet more questions: 78 of them in fact.
- In the Gospels we have a record of some 248 questions asked by Jesus.
- If we think we have an answer for everything, then perhaps we have not confronted the question.
- We can give no easy answers, but instead just make good responses.
- The Christian answer to suffering is rarely an explanation but a presence.
- Being truly present with someone confirms their uniqueness and carries with it unconditional acceptance. It gives them value.
- Dr Sheila Cassidy: *“Pain is part of the human condition and sharing that pain is a deeply human task”*.
- The words *“wound”* and *“blessing”* have the same Old English roots.
- Parents face *“the death of the imaginary child, and the redirection of parental love to the newly perceived child in reality”* (Prof Joan Bicknell).

- Aristotle (384-322BC) said: *“When I consider the younger generation I despair for the future of civilisation”*.
- The Royal College of Nursing 1997 questioned 4,295 11-16 year olds.
86% fretted about the way they look.
60% of 15 year old girls wanted to lose weight, and
78% of 17 year olds were unhappy with their bodies.
(Quoted in *The Times* 1997).
- *“Good sex is built on good communication not good bodies”*. (MONROE, 1998)
- C.S.Lewis once said: *“If there is meaning in life at all, then there has to be meaning in suffering.”*
- Dostoyevsky once said: *“The secret of man’s being is not to live but to have something to live for.”* Or as someone else put it: *“Better to die for something than of something”*.
- Viktor Frankl, the Austrian psychiatrist, was fond of quoting Nietzsche: *“He who has a why to live can bear with almost any how”*.
- *“The heart of spirituality is about the transcendence of one’s own self and the forming of deeply loving and compassionate relationships with others.”* (Anthony Seldon, headmaster of Wellington College.)
- **Spirituality** is a quality of life issue. In fact there is *“a growing awareness of the contribution that spiritual well-being can make to patients’ actual and perceived health and quality of life”*. (BRADY et al, 1999; CHIBNALL et al, 2002. Mont, 2003).
- There is certainly *“a growing body of evidence ... that spirituality enhances health.”* (COYLE, J., March 2002. *Spirituality and Health*. Journal of Advanced Nursing. Vol. 37)
- **Religion** is the ritual or liturgy we use to express and focus our spiritual beliefs. And this may be expressed by, and may include:
 1. Religious rites
 2. Prayer
 3. Sacraments
 4. Fasting
 5. Blessings
 6. Dietary requirements
 7. Creed
 8. Worship
 9. Code of ethics

(Harrogate Health Care NHS Trust – Spiritual Care Policy)

- What do we mean by spirituality? MURRAY & ZENTNER. 1988, speak of spirituality as “*a quality that goes beyond religious affiliation, that strives for inspirations, reverence, awe, meaning and purpose even in those who do not believe in any god. (Cited in MCSHERRY. 2000).*”
- Jean Vanier says “*Each of us has an instrument to bring to the vast orchestra of humanity, and each of us needs help to become all that we might be*”. VANIER, JEAN., 1998. *Becoming Human*. DLT. ISBN 0 232 52336 3
- “*There is no profit in curing the body if in the process we destroy the soul*”. Anon.
- A checklist to recognise spiritual need. *Harrogate Health Care NHS Trust and their Spiritual Care Policy*. Available from www.mfghc.com.
 1. Anger – Directed at God or other people.
 2. Bitterness – “*What have I done to deserve this?*”
 3. Regret – “*I should have been a better person.*”
 4. Guilt/punishment – “*I must have done something wrong.*”
 5. Doubt – “*Is there a God, is there really a purpose for existence?*”
 6. Fear – “*I am not sure there is anything after death.*”
 7. Isolation – “*My family/friends/neighbours/God etc. have abandoned me.*”
 8. Loss of hope – “*I see no future*”
 9. Tearfulness.
 10. Questioning/meaning of suffering/life/death.
 11. Nightmares/sleep disturbance.
 12. In denial.
 13. Withdrawn.
- How can we be sure that we are meeting spiritual need?
A checklist of questions.
 1. Are we “being there” for the patient, standing alongside them in their spiritual distress, available and approachable?
 2. Do we provide privacy, dignity, and a secure caring environment?
 3. Does the patient have good symptom control and a better opportunity to explore deeper issues?
 4. Do we provide a listening ear to enable the expression of feelings of fear, anger etc?
 5. Are we giving reassurance about physical care and pain control?
 6. Do we show respect for patient’s integrity, worth and values?
 7. Are we supporting the patient’s family?
 8. Do patients need help with “unfinished business”. Is there anything they need to do or say?
 9. Are we mindful that as physical health recedes, the spiritual dimension may grow in importance?
 10. Giving complete attention to a patient’s spiritual care.
- CLINEBELL, gave us a framework of four spiritual needs:
 5. The need for meaning and purpose in life
 6. The need to give love
 7. The need to receive love

8. The need for hope and creativity.

CLINEBELL, H.J. 1966 Basic Types of Pastoral Counselling: New Resources for Ministering to the Troubled. Abingdon, New York.

- **Coming to the end**

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And this should not be seen as the relinquishing of all hope. There comes a time when death should not be seen as the worst thing that can happen on a spiritual journey.

But the final stages of a person's life are timeless and precious moments. And the dignity of the death is preserved when:

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6. Any advance directives should have been explored which ensure that their wishes are sought and respected.
7. There should be time to say goodbye, to leave when it is time to go.

(Source unknown)

All these are recognition of their uniqueness, and a respect for our common humanity, and so reflect good spiritual care.

- **Examples Therapeutic Rituals**, which can be spiritually cathartic in grief.

1. **Balloons** - collect thankyou's, questions, things that need to be said, sorrys, goodbyes. Attach to helium filled balloons and release to the sky as a prayer.
2. **Fountains** - collect drops of water from "The Fountain of Tears" using a small bottle, which can then be labelled with whatever makes them cry.
3. **Display** - collect photos, examples of work and creativity, achievements, favourite things, and display as a celebration of their own life or their loved one's life.
4. **Scrapbook** - collect memories and feelings and make a scrapbook.
5. **Cushions** – made from an item of clothing belonging to the deceased person.
6. **Candles** - light candles, perhaps scented with a scent that reminds them of the loved one. This symbol of light, overcoming the darkness is like a prayer. Perhaps light the candle on special anniversaries.
7. **Prayer** - Write prayers or poems of gratitude, anger, confession, praise, and use them privately or with others.
8. **Flowers** - choose the flowers and place them in a significant place. E.g. roadside, grave, favourite place of memories. Stuffed toys, personal items, football scarves etc. Drop them into a flowing river.

9. **Coloured salt** - colour salt using wax crayons to symbolise memories and layer in a bottle to keep safe as a gathering of memories.
10. **Smash plates!** - or find something through which anger can be expressed against God or the loved one in a safe and loving place.
11. **Pilgrimage** - visit symbolic places, gravesides, places of fond memories, places of life's transitions, and grieve there.
12. **Stones** - Decorate little bag and place three stones in it - one a rough stone representing tough times; a smooth stone representing happier times; and a gem stone representing very precious memories.

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- STOTER, DAVID., 1995. *Spiritual Aspects of Health Care*. Mosby. ISBN 0 7234 1955 8.
- REPORT OF A WORKING PARTY. *Mud and Stars: The Impact of the Hospice Experience on the Church's Ministry of Healing*. 1991. Sobell Publications.
- VANIER, JEAN., 1998. *Becoming Human*. DLT. ISBN 0 232 52336 3
- CROSSLEY, DIANA., 2000. *Muddles, Puddles and Sunshine*. Winston's Wish – an activity book to help when someone has died. ISBN 1 86989058 2.
- FRANKL, VIKTOR., 1946. *Man's Search for Meaning*. Washington Square Press Publication. ISBN 0671 02337 3.

Websites

- www.mfghc.com - The Multi-Faith group for Healthcare Chaplaincy.

At this resourceful site the following are available:

The concise guide to the customs of religious culture and practice. 2005. Lancashire Teaching Hospitals NHS Foundation Trust

Extracts from "*understanding and respecting religious and cultural needs: respect for privacy, dignity, religious and cultural beliefs*". 1997. University Hospitals Birmingham NHS Trust

Faith Requirements Resource Pack. 2003. Bradford Teaching Hospitals NHS Trust

Policy for ensuring that religious beliefs are respected. 2003. Queen Elizabeth Hospital NHS Trust

Respect for privacy, dignity and religious and cultural belief. 2004. The Oakhill Trust in conjunction with Bromley Hospitals NHS Trust

Respecting religion at work. 2003. Plymouth Hospitals NHS Trust

Respecting religious and cultural beliefs: a best practice guide for those involved in the welfare of patients. 2005. South Warwickshire Combined Care NHS Trust

Spiritual and cultural care policy directory. 2003. North Middlesex University Hospitals NHS Trust

The religious, spiritual and cultural needs of patients: a guide and reference document for staff. 2002. Derby Hospitals NHS Foundation Trust

Understanding patients' needs: a guide to cultural, spiritual and physical needs. 2004. Burton Hospitals NHS Trust

Spiritual Care Policy. 2004. Harrogate Health Care NHS Trust

Spiritual Care Policy. 2003. Basildon and Thurrock University Hospitals NHS Foundation Trust

Cultural, religious and spiritual awareness in healthcare settings. 2004. Newcastle, North Tyneside and Northumberland Mental Health NHS Trust

Encountering Cultures: an opportunity to learn more about faith communities. 2004. College of Health Care Chaplains, Northern and Yorkshire branch

- www.treloar.org.uk

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FARVIS, R A., *Ethical Considerations in Spiritual Care.* 2005. International Journal of Palliative Nursing, Vol 11, No 4.

HUNT, J., COBB, M., KEELEY, VL., AHMEDZAI, SH., 2003. *The Quality of Spiritual care – developing a Standard.* International Journal of Palliative Nursing, Vol 9, No 5.

MILLIGAN, S., 2004. *Perceptions of Spiritual Care among Nurses undertaking Post registration Education.* International Journal of Palliative Nursing, Vol 10, No 4.

YIN LOH, K., 2004. *Handling Spiritual Questions of Terminally Ill Patients.* International Journal of Palliative Nursing, 2004, Vol 10, No 11.

GATRAD, AR., SHEIKH, A., 2002. *Palliative care for Muslims and Issues Before Death*. International Journal of Palliative Nursing, Vol 8, No 11.

OATES, L., 2004. "Providing Spiritual Care in End-stage Cardiac failure" International Journal of Palliative Nursing, Vol 10, No 10.

BYRNE, M., 2002. *Spirituality in Palliative Care: What Language do we need? –*. International Journal of Palliative Nursing, Vol 8, No 2.

GOVIER, I., 2000. *Spiritual Care in Nursing: A Systematic Approach*. Nursing Standard. January 12/vol 14/no 17.

HIGHFIELD, M., CASON, C., June 1983. *Spiritual Needs of Patients: Are They Recognised?* . Cancer Nursing.

REES, C., JOSLYN, S., 1998. *The Importance of Hope*. Nursing Standard. Vol 12, No 41.

HOWLETT, C., WWAIN, MS., FITZMAURICE, N., MOUNTFORD, K., LOVE, P., *Sexuality: the Neglected Component in Palliative Care*. International Journal of Palliative Nursing, Vol 3 Issue 4.

CAWLEY, N., *An Exploration of the Concept of Spirituality*. International Journal of Palliative Nursing, Vol 3, Iss. 1.

NARAYANASAMY, A., *Spiritual Care of Chronically Ill Patients*. British Journal of Nursing, Vol 5, Iss. 7.

KENNY, G. 1999. *Assessing children's spirituality: what is the way forward?* British Journal of Nursing, Vol 8, No 1.