



No box to tick

A booklet for carers of people with learning disabilities

Between 2002 and 2004, Professor John Swinton and Elaine Powrie from the University of Aberdeen carried out research with people with learning disabilities about their spirituality. They asked them about what gives meaning to their lives. This booklet is based on what they were told in interviews and focus groups. The Foundation has also published a booklet for people with learning disabilities, based on the research, called *What is important to you?*

This booklet was written by John Swinton and edited by Hazel Morgan.

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Introduction

Carers usually have to spend a lot of their time supporting people with learning disabilities in meeting their physical needs and helping them acquire new skills. There is not much time for thinking about spiritual and emotional needs, but people with learning disabilities have told us how very important these are to them. Therefore we have written this booklet for support staff and others who wish to learn more about these dimensions of the lives of people with learning disabilities

What is spirituality?

The idea that spirituality might be an important part of people's lives might seem strange. After all, is it not the case that fewer and fewer people are attending churches? Are people not fed up with religion? Well, it is true that less people are involved with established religion. However, surveys suggest that people are still very interested in spirituality. Spirituality and religion are not necessarily the same things. It was clear from the experiences of the people with learning disabilities who took part in this study that the word 'spirituality' had a much wider meaning than religion alone.

For me spirituality is those feelings people get that make some people want to run out and start religions. Personally, I don't believe in a God - a divine being - of any description. That's just my personal beliefs. But I do have a great wonder at the workings of the world and the universe. I suppose you could call that a spiritual response. I don't necessarily think religion and spirituality go together.



People felt that spirituality had to do with such things as the search for meaning and what is most important in life, what gives value, hope, friendship and purpose as well as, for some people, their relationship with their God. For some this involved religion, but for many others the spiritual search was carried on without the use of formal religion or belonging to a faith community.



It was clear that spirituality had a wide range of meanings for people and that they used various ways of finding fulfilment. People said that their spiritual needs were met through their friendships, through involvement in communities where they felt a sense of belonging and value, by finding ways of getting in touch with nature and the wonder of the world, or by expressing the things that were most important to them through music or art. Each person was different. Some found meaning to their lives through involvement in formal religions.

Things to do

- Think about what gives meaning to your own life. You might like to discuss this with a colleague or a friend.
- Take some time and ask the people you are working with what it is that gives them meaning in their lives. Share your own thoughts and feelings and talk together about your answers.

The importance of friendship

If you don't have friends you wouldn't go out and you'd be left all on your own. You wouldn't have any contact with anyone.

The word that seemed to sum up the essence of people's understanding of spirituality was connections. People felt spirituality had to do with being connected with friends, with a community and for some people with God. The most important way that people felt connected was through their friendships. Friendships gave people a sense of meaning for their lives and offered them purpose and hope for a positive future. Friendships affirmed people's sense of value and provided them with the feeling of acceptance and being loved. These things are all important aspects of spirituality. Lorraine explains the importance of friendship in this way:

My opinion is that friends are important. I can't think of anything more important that I need to get me through life.

People felt that the type of friendships they had was important. Some were keen to develop friendships with their carers and support workers. But they also wanted to have friendship with people who were not family or paid to be with them. The types of friendships that people most wanted were those where they felt that they were singled out and chosen not because they had a learning disability, but because people simply liked them and wanted to spend time with them.



Loneliness

Although everyone we spoke with wanted long-term committed friendships, the reality for many was that they found it very difficult to find friends. Many people told us that they were lonely and that they found it hard to make friends. They rarely got the opportunity to meet others and get the chance to make meaningful friendships. They also needed support to make arrangements and to keep in touch. Loneliness and a sense of disconnection were therefore important spiritual problems that people encountered. Roland summed up the experience of many people:

Interviewer: *Have you ever felt love in your life?*

Roland: *No, not really, I've been lonely all my life.*



Things to do

- Ask people about their friendships and how important they are for them.
- Take action to ensure that people are given space and encouragement to spend time with their friends and for their friends to visit them.
- Help people to find opportunities to meet people. Are there any community groups in your area that might be good places for people to go and meet people, for example, People First groups or a faith community?

Losing people we love

Spirituality has to do with connectedness and relationships. Because relationships are so important to people, losing these relationships can be extremely difficult for people to cope with. People lost their relationships in two ways:

- When people moved on due to changes in employment, moving house etc.
- When people died.

When people we love move on

For some people the main friendships they had were with the staff who offered care and support to them. Sometimes people had been together for long periods of time and had developed deep and meaningful friendships. When staff moved on this left a huge hole in people's lives and for some people, became a significance source of grief and sadness. Such losses were deeply spiritual inasmuch as a person's relationships are one of the main sources of value and meaning. To have this source of value and meaning taken away, sometimes quite suddenly, could be very difficult for people. Some staff take a lot of trouble to prepare people when someone is leaving.

Things to do

- When people are leaving your work situation, mark the occasion with some kind of ritual or celebration. This will help people to come together and acknowledge their sadness and give them an opportunity to move on.
- Offer continuing comfort, support and understanding to people who may be upset when people move away. It may take some time before the sadness and sense of loss really hits them.
- Make a note in your diary to go back and speak with someone whom you feel might be upset after a person has left.

When people we love die



The second and greatest cause of grief and loss occurred when people lost loved ones through death. Some people simply accepted the loss and moved on. Others developed ways of feeling connected with their loved ones even though they were no longer with them. People would keep mementos or photographs of people who have died. Having these and thinking about what they symbolised seemed to help people cope with losing someone they love. This seemed to help them to continue to feel connected with the person who had died.

However, some people had not coped well with their grief. It was clear as we talked with people that many were still wrestling with unresolved grief. People were clearly still grieving for loved ones who had died in the past, sometimes twenty or thirty years previously. People told us that they had never really had the opportunity to tell anyone about how they felt. This was a source of distress and concern for some people.

As we spoke with carers and support workers, the reasons for this became a little clearer. For some carers and support workers, dealing with death and loss was not easy. People found it difficult to broach the issue for fear that open discussion of death and loss might be distressing for people. As one carer put it:

Inadvertently you can tap into very deep emotion and maybe that's something you have to be mindful of - not to leave people hung and dry.

Issues of grief and loss are difficult areas that need to be approached carefully and sensitively. Nevertheless, the people with learning disabilities we spoke with wanted carers and support workers to discuss these things with them in order to give them the opportunity to tell people about the difficulties they were encountering.

People seemed to find the focus group setting a helpful place to talk about these issues. People were often very supportive of one another and helped each other to deal with some very deep and troubling issues. They sympathised with others in ways that allowed them to express the deep sadness they were feeling and feel safe in doing so. If people can find the confidence to ask questions around difficult issues, it can be a healing and growing process for all concerned.



Things to do

- People with learning disabilities do not have different grieving needs from the rest of the population. They require to be listened to and assisted in re-building their lives after the loss of a loved one. Recognise this yourself and help others to do the same.
- Create opportunities for people with learning disabilities to discuss issues of grief and loss in an atmosphere that is open and supportive.
- Ask for training which will enable you to feel comfortable working with this area of people's experiences.
- If you think someone is struggling with grief, get help for them.

Celebrating together



The people with learning disabilities we spoke with felt that celebrating together was important. Sometimes these celebrations were religious and took place in services of worship. People celebrated particular religious festivals such as Christmas, Passover or Eid. When people participated in such celebrations they were enabled to develop a sense of being part of a community and it improved their quality of life in important ways.

People also seemed to enjoy other forms of celebration such as birthdays, anniversaries and similar special occasions. This type of celebration involved getting together with friends and those whom people cared for and together taking time to appreciate one another and to share in something special together.

Things to do

- See if the person you support might want help with a celebration.
- You could perhaps go with someone when they attend a religious celebration. Even if you don't share their beliefs it will be useful to find out what it means for them and what goes on when they attend their faith community.

Finding a quiet place



I think tranquillity is something you rarely get. There are very few places in the world where there is tranquillity. Sometimes, I feel as though I need space, but I find it difficult in like this environment because...it's very difficult.

While community celebrations were important to people, the opportunity to be alone was also important. Some of the people we spoke with led busy lives. People sometimes had jobs or attended day-centres. This took up much of their time and could sometimes be quite stressful. People found that they had little time to think about what was really important to them. It was clear that many people were unhappy living this way and longed to be able to find space in their lives within which they could concentrate on themselves and what was important for them and perhaps encounter something beyond themselves. People wanted space to sit, reflect, pray or simply relax and find some peace and quiet. Providing the opportunity for people to find space to reflect and to think about their day can be a powerful source of spiritual support which can improve a person's sense of well being and quality of life.

Things to do

- Make sure that people get the opportunity to find somewhere where they can take time out and reflect on their day or their lives. This can be their room at home or it can be a special place set apart within the workplace if this is practical.
- Ask people if this is important for them.
- If a person is religious, you could give them the opportunity to spend some time in buildings such as churches, temples, synagogues or mosques. This time doesn't need to be during a service of worship. People can use religious buildings as places to go to find space and peace.

Believing in God

Some of the people we spoke with worked out their spirituality without the help of religion. However, for others religion remained a very important aspect of their lives. Believing in God gave people a sense of being valued and marked out as “special” and “specially loved.” As Jenny put it:

I was born with a hole in my heart. When I was little it needed a patch and I was very ill. It might be because of this but I have always felt special...God is my best friend. God made me special because I was special to him'.



Faith communities

Belonging to a religious community and/or believing in God was a powerful source of support and well-being in some people's lives. Religious communities gave people the opportunity to develop a sense of belonging and to find a meaningful place within the community. Things like praying, reading religious scriptures or attending services of worship were very important for some people. A Muslim woman who has two children with learning disabilities, described how her 19-year-old son, Ahmed, who has profound and complex needs, is active in her mosque and takes great pleasure in learning about and participating in their religion. Ahmed is more enthusiastic about Islam than her other children. Although he is English speaking, he has spent a lot of time learning the Qur'an in Arabic, primarily by copying other children within their religious community.

Allah gave him the ability to read Arabic, no one taught him- he just copied others- he was never forced to learn at all.

Ahmed regularly goes to the mosque with his father and is fully integrated in the religious community where he has a solid and recognisable role. People have gone out of their way to facilitate his spiritual development although Ahmed's mother emphasised that there is a great need for information on Islam in symbolic and pictorial form for people with learning disabilities.

Faith communities and friendship

Faith communities are a potential source of friendships for people with learning disabilities. They can provide a place where people with learning disabilities can have the opportunity to develop positive spiritual relationships with others and with God. Some communities are more welcoming than others. We discovered some faith communities where people with learning disabilities were fully accepted and well integrated and in which they had been able to develop strong spiritual friendships. However, a number of people with learning disabilities felt that the friendships they received within faith communities were sometimes at a superficial level. People within faith communities tended to offer friendship during and immediately after services of worship, but rarely if ever were people invited back to their homes. Ina's experience is just like this:

Interviewer: *So do you go to meetings during the week or do you go to people's houses or do you just see them at mass?*

Ina: *Just see them at mass.*

At one level Ina's quest for friendship has been fruitful. Within the boundaries of the religious service of worship she seems to have found acceptance and, at a certain level, friendship. However, that acceptance and friendship appears to stop at the door of the chapel. She has never been invited into the homes of her religious friends, although clearly she desires to be.



Inclusive practices

Some faith communities went out of their way to incorporate people with learning disabilities. Some made a conscious effort to incorporate people in every dimension of their community's life. Some communities worked to enable people to understand and participate in the sacraments, in the worship, in the teaching and communicating of their scriptures and in the relationships which made up the community. It was clear that given adequate support, encouragement and education faith communities could be invaluable in developing the spiritual well-being of people with learning disabilities.

Michael meets Steven at the church every Sunday. Steven sits beside Michael during the service and they sing and pray together. As soon as the band strikes up Michael and Steven stand together, clap their hands and have a great time enjoying the music.

Exclusive practices

However, some faith communities could be exclusive. People with learning disabilities felt that they were excluded by the ways in which the faith communities presented their message. The teaching, liturgy, prayer and worship used by some faith communities was often wordy and highly intellectual which meant that many people with learning disabilities were excluded from taking part because they simply did not understand what was going on. It was clear that if people with learning disabilities were to be able to find a place in faith communities, these communities would need to re-think some of the ways they go about things.

Things to do

- Recognise and respect the fact that religion is important for some people.
- Use the Good Practice Guide on Meeting the Religious Needs of People with Learning Disabilities (see page x).
- See if the person you support wants to have the opportunity to attend worship and to participate in their particular faith community.
- If a person has a religious faith they should be given the opportunity to pray or access their religious teaching, even if carers or support workers do not share that particular tradition.
- Faith communities might want to reflect with people with learning disabilities on how their forms of worship can be made more accessible.

Using people's talents and skills

One important way that people with learning disabilities expressed their spirituality was through the use of their creativity. People used music, art, storytelling and other forms of creative activity to express what was most important to them. When people felt tired or down, their spirits were often lifted through listening to or playing music or singing songs which seemed to inspire and energise them. Music in particular seemed to raise people's spirits and allowed them to express feelings of happiness, sadness and other deep emotions which could not be expressed in words but which were nonetheless of great importance.



People also used drawings and paintings to express the way they felt about the world, themselves and God. Some people liked looking at pictures and photos.

Seeing these pictures makes me believe that God exists, the beauty in the world...there is beauty in the world

Things to do

- Create opportunities for people to express their inner feelings through the use of their creativity. For example, listening to music can bring back memories and give people a sense of wholeness and connectedness.
- Find out what stories are important for the people you work with.
- Get together and read stories that are linked to a person's culture and religion. This can help them to feel part of a community that stretches beyond their own circle of friends.
- Help the person you are with to write or tell their life story. This will help them to see where they have been and where they hope to go to.
- Use art to enable people to express their emotions and inner feelings.

Things that get in the way of spiritual care

Most of the carers and support workers we spoke with recognised the importance of the spiritual dimension of the lives of people with learning disabilities. However, people encountered a number of difficulties when it came to putting spiritual care and support into practice. One of the main problems was that they were uncertain about what spirituality was and how it related to their day-to-day work. People had not had any education or training in this area, so it was difficult for them to recognise and explore it. As one support worker put it:

There's not a box to tick to say "I have helped Bruce think about mortality". There is a box to tick to say "I've cooked the tea" and that "it was wonderful."

Most people felt that they simply did not have time to deal with the types of issues that people raise under the banner of spirituality. It is not that people felt that spirituality was unimportant. They simply didn't have time to do all of the things they felt needed to be done. Where people are overstretched, under-staffed and under-supported addressing spiritual needs can appear to be an unnecessary burden. There were also some families who simply didn't have the time or the necessary support to be able to cater effectively for their family member's spirituality, despite a deep and genuine desire to do so.



Whilst some people were clearly aware of the significance of both religion and spirituality, others were less clear about its value for their areas of practice. Sometimes this was expressed directly, but sometimes it came through indirectly through people's assumptions and practices. For example, within one care home carers described the home as having a busy timetable during the week and stressed the importance of service users staying in on a Sunday for "chilling out." Attending a service of worship was viewed as an infringement on this time out. Residents within that home didn't attend services of worship. This was despite the fact that a number of people living there told us they would like to do so. The problem seems to have been that they were never asked and did not feel confident enough to make this request.

Things to do

- Recognise that spirituality may be important for the people with whom you work.
- Think about the importance of spirituality for your work and discuss with your colleagues the significant barriers which might prevent effective spiritual care and support.
- Ask for training and support to help you recognise and deal with spiritual issues.
- If you are a manager, take seriously the problems of time and under-staffing in order that the spiritual dimensions of the lives of people with learning disabilities can be respected and cared for.



Further Resources

Books and articles

- Swinton, J., and Powrie, E. (2004) *Why are we here? Meeting the spiritual needs of people with learning disabilities*. London: Foundation for People with Learning Disabilities.
- Swinton, J. (2001) *A Space to Listen: Meeting the spiritual needs of people with learning disabilities*. London: Foundation for People with Learning Disabilities.
- Hatton, C., Turner, S., Shah, R. Rahim, N. and Stansfield, J. (2004) *What about Faith? A good practice guide for services on meeting the religious needs of people with learning disabilities*. London: Foundation for People with Learning Disabilities.
- Hatton, C., Turner, S., Shah, R. Rahim, N. and Stansfield, J. (2004) *Religious Expression, a Fundamental Human Right: The report of an action research project on meeting the religious needs of people with learning difficulties*. See: www.learningdisabilities.org.uk
- Crompton, M. and Jackson, R. (2003) *Spiritual Well-being of Adults with Down Syndrome*. Southsea: The Down Syndrome Educational Trust.
- Oswin, M. (1991) *Am I Allowed to Cry? Study of Bereavement amongst People who have Learning Difficulties*: Souvenir Press.

Useful Organisations

- Circles Network
Pots Dam Farm
Coventry Road, Cawston
Rugby CV23 9JP
Tel: 01788 816671
Email: information.circles@btconnect.com
Website: www.circlesnetwork.org.uk
Circles Network can give information about someone setting up a Circle of Support with family and friends.
- Heart 'n Soul
Website: www.heartnsoul.co.uk
An organisation that seeks to use art to touch and change people's lives.
- CRUSE - Bereavement Care
126 Sheen Road, Richmond
Surrey TW9 1UR
Tel: 0870 167 1677
- Carers National Association
Ruth Pitter House, 20-25 Glasshouse Yard
London EC1A 4JT
Tel: 020 7490 8818
Helpline: 0808 808 7777 (Monday to Friday 10am-12 noon & 2pm-4pm)
Fax: 020 7490 8824
Email: internet@ukcarers.org



We use research and projects to promote the rights of people with learning disabilities and their families.

We do this by:

- Identifying work that is needed to overcome barriers to social inclusion and full citizenship.
- Communicating our knowledge to a wide range of people.
- Turning research into practical solutions that make a real difference to people's lives now and in the future.

Foundation for People with Learning Disabilities

83 Victoria Street

London

SW1H OHW

Tel: 020 7802 0300

Fax: 020 7802 0301

Email: fpld@fpld.org.uk

www.learningdisabilities.org.uk

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