

Module 4 - Caring about Carers

Facilitator's Guide:

You will need:

- A flipchart and pens to capture the points made during the meeting.
- Sufficient copies of the factsheet and testimonies for members of the group.
- Paper for sub-groups to record their thoughts.

Aim of this module:

- To understand the experiences of carers and family members in caring for someone experiencing mental distress.
- To understand and identify how we might be able to support carers in our parish or deanery.

Programme/Plan for this module:

Length of session: 90 minutes to 2 hours

Opening Prayer (5 minutes) (see below)

Introductions and Ground Rules (See Introduction) (10 minutes)

Scripture reading. There are several scripture passages which link with the theme of this module. (15 minutes)

Discussion: Thinking About the caring role. In our parish communities carers often find it difficult to take an active part. They may often have obligations at home or feel perhaps reticent in accompanying their loved one when their behaviour could be seen as unusual or challenging. For this reason carers need to be made welcome and understood.

The term 'carer' has been given prominence in recent years through a focus on the burdens of care and the need to recognise that carers should not just be relied upon at the expense of statutory services. But some carers might feel uncomfortable with the label 'carer' and prefer to see themselves as 'Mum' or 'Dad'.

Care giving is a natural process and is not simply an activity. Care giving is a mixture of behaviour, feeling and emotions. Some of these emotions are based on love in spite of the daily challenges of looking after a loved one, while others are based on more complex feelings of anger and guilt.

Using the flipchart, ask participants to list the emotions involved in caring. You might want to divide the sheet into positive and negative emotions so that participants focus on the positive as well as potentially negative dimensions of the caring role. (30 minutes)

Testimonies: Ask participants to read the stories of either, Stephen, Edna or James (You might ask the group to split into smaller groups to consider these testimonies). Consider the questions linked to the testimonies. (30 minutes)

Summary: Distribute the factsheet and potential ideas for carer support. Ask the group to consider the implications of the discussion for pastoral and spiritual support offered by the parish or deanery. Distribute the prayer resources to those interested. (15 minutes). Finish the session with a closing prayer.

Opening Prayer – Here is an opening prayer written by someone who died recently. You will find other possible prayers in the resources section.

Your strength Lord, is in us

When the pressures of life are just too much. We just can't cope and really lose touch. From our illness there is no immunity but you know we need your community. The people out there are our sisters and brothers and what has happened to us will happen to others. This is your strength within us, Lord. We know it. We have your gift of compassion to show it. We pray to you, that we use it to benefit others, Your Church, and our sisters and brothers. Give us a positive attitude to mental health awareness. Why the stigma? Where's the fairness? We believe we understand the position. Give us your strength to work on this mission. *(Ad Majorem Dei Gloriam: To the greater glory of God)* Nick McCreton

Stephen's story

I am organist at our local Church as well as being a Eucharistic Minister. I am also Vice-Chair of our Parish Council. Our son has suffered from a psychotic illness for the last five years. Last Christmas he had to be compulsorily admitted under a section of the Mental Health Act. I found the experience very difficult but when I tried to talk about the psychiatric ward after Mass over coffee I felt people around me didn't know what to say. It's so much easier to talk about someone suffering from a physical illness, but when it comes to mental illness, people seemed embarrassed to talk about it – I felt that I just couldn't share my feelings. I felt uneasy about adding our son to the list of the sick for the bidding prayers. My question is – 'How can we make mental illness an OK subject to talk about?

Stephen's prayer

We saw our son today on the Mental Health Unit. His eyes were glazed over and he couldn't decide if he should come out of his cubicle. Perhaps his voices told us that he couldn't be sure of us...or perhaps he was just too exhausted after his compulsory admission earlier in the week, just two days after Christmas. All the world seemed too much for him as he turned back to his bed, laid down and tried to get some more sleep.

Lord, I've been trying to understand the terrible experience of psychosis in our young son. When the world is so full of opportunity, its so hard to understand that your creative goodness should pose such a burden on such a young life. When family and friends become too much and the bedroom is the only refuge for 24 hours a day and when nothing else matters other than retreating from the world.

Lord, we are back at home now. In the darkness of the winter evening, perhaps you can help us to find some meaning in the emptiness we feel tonight. In the peace of our living room we have lit a candle for our son. We've put it next to the crib, symbol of your creation. Exhausted and bewildered, we turn to you.

Help us to cherish the goodness and personhood of our son who has been created and shaped in your own image. Help him to glimpse once again a world of meaning and love.

And in the darkness and confusion of his cubicle on the ward, be present to him and shine your light of love and hope.

Amen

A question for discussion: How can we help parishioners such as Stephen? How can provide support and help to those in a Mental Health Unit and their carers?

Edna's story

My Mother suffered from a compulsive obsessive disorder which began to manifest itself more acutely in the years after my Dad died. I became the person to whom she could off-load her obsessions, pleading with me for advice as no-one else must know! She was clever and articulate but inside her four walls was tortured by her disorder. She telephoned me frequently. This was on-going and then, Elizabeth, thirteen, and youngest of our eight children, became seriously ill. Eventually we saw a consultant psychiatrist at an emergency appointment at St. Luke's hospital, a very old mental hospital but modernised although its reputation hadn't moved at the same pace. When I told Elizabeth where we were going, she was horrified. She said, 'you know what they say about that place, Mam. They call it the 'looney bin' where the 'nutters' and 'psychos' go', this kind of language still used in our society. By turning a person into a label, we take away their dignity, their personhood and dehumanise them.

Elizabeth was very ill, in a severe clinical depression caused by a chemical imbalance triggered off at puberty, and a patient at the hospital. Everything had to go on hold, no school, no homework, no music lessons. She was a clever girl. We had been told at her last open evening at school that she would probably do maths at university. She had passed five grades of cello and four of piano. She never again put in a full week at a time at school because of this illness. However, I was told that because of her age, it was thought that staying over night at the hospital may do her more harm than good, that I could take her home each evening but not to let her out of my sight as they did not know her 'flip point'. In other words, she was suicidal and on a twenty-four-hour watch. I took her home and I did not know what to expect. I was not a trained professional. I am a mother, a grandmother. That was early May.

The days ran into weeks, into months and I looked after Elizabeth mostly at home with many visits to the hospital. It was very stressful with Elizabeth's mood swings and tears and devastating on our family relationships. In the August, the psychiatrist wanted Elizabeth back in hospital because she was so ill and thus, I went to see a priest because up to this point we hadn't had a visit from one although they were praying for us but I needed a Christ-in-the-flesh. I asked the priest if he would come to our home and pray with our daughter and us. He was a kind and gentle man, humble and very honest. He said, 'Edna, I know my limitations and I'm not very good with teenagers and I don't know your daughter very well. I was trained forty years ago and I know next to nothing about mental illness and I'm frightened that if I come I may do more harm than good.' I asked him if he could recommend anyone else and he said that he couldn't. I went home alone. I was slowly becoming a broken carer. I needed a compassionate Christ. I thought a lot about this. I think that we are a good Church at supporting families where there is sickness and suffering and I suspect that had our daughter been experiencing a different sort of life-threatening illness, we would have had more

support. I wondered, was there a gap in pastoral care with reference to mental illness.

I was doing my BA degree in Divinity at the time as a very mature student studying from home distance-learning. I decided that when I got my degree I would continue with a Masters degree because I knew I'd be allowed to choose my own research topic and I wanted to look at this area of pastoral care within the Church. I wanted to see if there was a gap or was it just our family that I felt had fallen through the net.

As part of my research for a Masters Degree, I interviewed at length four Catholic clergy still active today in our diocese, about support for families where there is sickness and suffering including where there are mental illnesses. I looked at the documents of Vatican II and found enough to support this area of pastoral care. I sent questionnaires out to two Carers support groups, one of which I initiated with the help of a priest and it has been on-going ever since, as carers come and go. We begin with a short Scripture Reading because I needed to meet Christ in all of this. One day, a carer telephoned me. She said, 'Edna, I've been thinking of coming to your support group for some time now but I'm frightened that if I do, it will get out.'

The stigma of mental illness! She didn't want anyone to know what was going on in her family. I reassured her that what was said was treated confidentially and she came and told her story. We share our joys and sorrows, and sometimes our tears and we say a little prayer.

I submitted all my research and the Examining Board gave me a distinction and said they hoped that I would get it published in some form, which is what inspired me to write my book, *Carers in the Community: 'Why have you forsaken me?'* re-published in 2009 entitled *Our Suicidal Teenagers: Where are you God?* It contains six years of our journey with our daughter through her teens including her relapses and the effect on our family relationships; how I went about setting up a carers pastoral support group; and my Masters research.

Firstly, it is to give people hope because we are the lucky ones as we still have our daughter with us. In her late twenties, she finally achieved her 2.1 degree at the University of Durham and is now a primary school teacher and has two school children. Secondly, I hope the book will help in understanding the effects of mental illnesses on individuals and families. My second book also published in 2009, *Pastoral Care Mental Health*, is the compilation of 6 years research; results of responses to over 500 questionnaires; and some case stories.

I have met many people on my journey speaking in churches and at conferences, and heard many stories. I met a lady with bi-polar who is unable to face her Christian community at Mass. How does she receive spiritual nourishment? I met a lady with serious depression who does go to church but is reluctant to speak about what her life is really like. So as well as the Carers monthly pastoral support group, I also facilitate a

monthly pastoral support group for those experiencing mental ill health, which I began with the help of a priest, a number of years ago.

In conclusion, I think people with mental illnesses in our society today are among some of the most marginalized people. They lose their self-esteem and their dignity. They don't feel lovable and they have no status. Many people don't really want them in their back yards and as for applying for a job, do you put on the form where it asks about your mental health that you've been under a psychiatrist in your teens and/or still take medication and if so, will anyone employ you even if you are able to work? It's called discrimination.

I think if Christ was walking this earth today, He would be with these people and their families. He has our hands and our feet. So I hope that in raising awareness about the silent suffering that goes on behind four walls, there will be more understanding, acceptance, compassion, and support, so that on the Day of Judgment Christ can say, 'Come you blessed of my Father. When you did this to one of these my brothers and sisters, you did it to me' (Mt.25:40). Edna M Hunneysett

Some questions for discussion:

Edna's daughter experienced a mental illness at the age of 13. How might we better support young people in mental distress?

How can I be a compassionate Christ to an individual experiencing a mental illness? To someone who is suicidal? How can the Church community be caring?

How can I be a 'Good Samaritan' to someone who cares for a person with mental ill health? How can the Church community be supportive?

James's story

'James' had been a history teacher in a Catholic comprehensive school. He had been well regarded by his students and colleagues, and when he retired he played a valuable part in his local parish, working with the St Vincent de Paul Society. Sadly, in his early 70's James began to exhibit signs of dementia.

Fortunately, his wife, 'Louise' and his four children were all very supportive. But, as if often the case today, James and Louise's children were widely dispersed, two of them in fact living and working abroad. The burden then fell mainly on Louise, though James' old friends in the SVP were also concerned and kept in touch.

James still wanted to come to Mass, and Louise was very keen to help him do so. But at times James became panicky and claustrophobic in the parish Mass, and would sometime exhibit bizarre behaviour, which Louise and members of the congregation often found difficult and embarrassing.

After a few years, the strain began to tell on Louise, and James had to have a stay for respite in a local residential home. This home had not introduced policies and procedures around the assessment of an individual's spiritual needs, and had limited connections with community (including faith community) groups. James became isolated during these periods, especially when Louise was unwell, and during periods of lucidity, felt an acute loneliness and loss of his faith community.

Some questions for discussion...

How do we relate with people and their carers who may exhibit unusual behaviour in parish settings (it may include people with dementia, psychosis, autism)?

How can we best support carers in our parish communities?

Do we know about local mental health services and services provided by voluntary groups ?

For helpful information around the needs of carers and also people with dementia see chapters by Barbara Pointon; and Dr Susan Benbow, Kate Reed, and Ben Bano in Gilbert, P. 2011.

Some prayers with carers in mind

A Carer's Lament

I've cared for the Youngsters, the Old and Infirm.
I've nurtured the Ones with no prospects to learn.
I've spent many years with the Mentally Ill.
I've memories of these, which none other can fill.
I've spent sleepless nights tending Dying and Sick.
I've cared for the Troubled until mentally fit.
Like Jesus, whose once-darkened souls He has lit.
And now I am old, and as tired as can be, I wonder who's going to look after me?
Thank God, we've a Saviour who says he will not, for a moment forsake us, whatever our lot! *Ken Bunting*

My beautiful wife...

My beautiful wife has dementia.
She was neither a good cook or a very good housekeeper,
but she is a beautiful person,
beautiful within.
She has a beautiful spirit.
She has been my beautiful wife for sixty four years,
I love her with every fibre of my being.
She is my beautiful wife.
"A perfect wife, who can find her?
She is far beyond the price of pearls.
Her husband's heart has confidence in her." Proverbs 31. 10 -11
From 'Petals of Prayer' by Sr Siobhan O'Keefe (Kevin Mayhew Publications)

Dad no longer recognises me...

I came to see Dad in his residential home last Sunday. He wasn't able to recognise me and he thought I was his sister. He is not aware that Mum died a few years ago. I tried so hard to communicate with him and reassure him. I came away from my visit upset that he has deteriorated so quickly – his dementia was only diagnosed three years ago. He spends a lot of time in bed, seemingly oblivious to what is going on around him. I know I need to understand that this is the course of Alzheimers Disease - but its so difficult to see him in this state.

Today after Mass I had a talk with our priest. He reminded me that as Dad's mental and physical faculties fail, he needs me and the rest of the family to help him to hold on to his identity. We need to understand that Dad's spiritual self is still intact - and we can nurture it with memories, prayers and hymns which have meant a lot to him in his life.

Dad gets easily upset. But this afternoon I took one of his favourite hymn books to him. We sung together one of the old Welsh hymns he had sung in his childhood. It was lovely to see how his eyes lit up. He gets great pleasure from receiving Communion each Sunday from one of our Eucharistic Ministers.

Lord, I am here before you with Dad at my side. We are in his bedroom - on the walls are pictures of Mum and of special times for both of them. Help me to realise that he is still very precious in your eyes even as his mental and physical faculties fail.

In his weakened state, help me to see him as a gift to you and to us, a source of grace and inspiration to myself and our family.

I have wiped his face before I leave him today. Just as Veronica wiped your face as an act of love in your suffering, I give Dad this act of love - and I pray that he will be ever closer to you as his dementia advances.

Caring about Carers – Fact Sheet and ideas for Carer Support

Carer Assessment. Did you know that carers who provide 'regular and substantial care' are entitled to an assessment of their needs by the local authority? And their social as well as occupational needs have to be considered. While there is no statutory entitlement to a service following an assessment, carers can receive a carers grant, often a one-off payment. This should enable carers to take a break, or perhaps to enjoy the experience of a retreat – see below...

Children with caring responsibilities for their parents or other relatives are known as 'young carers', with a right to have their needs assessed in their own right. In many areas there are young carers support workers.

Caring for a person with dementia. Caring for a person with dementia can be challenging, particularly as dementia advances. Carers can feel reticent to bring their loved ones to Church and may feel it is easier for them not to participate in parish life. Even at the early stages of dementia when memory loss takes hold, carers may feel anxious about their loved ones taking part in activities which they previously enjoyed.

Consider how we welcome those with dementia and their carers Caritas Social Action Network recently produced a DVD on this subject – obtainable on www.csan.org.uk

Some ways in which we might support carers in our parishes and deaneries:

- *Read Edna's story. Her experience led her to setting up a support group for carers which enables carers to share their experiences in a safe and non judgemental climate. The groups which Edna facilitates also involve scriptural reflection and prayer. Do you have someone in the parish who would be prepared to act as facilitator for such a group? Edna is happy to provide advice and support – her phone number is:*
- *Carers often need some time and space away from their immediate situation. A day retreat for carers in a pleasant and nurturing atmosphere can help in that important process of recharging batteries. The Pastoral Care Project (www.pastoralcareproject.org.uk) has experience in organizing days for carers which are both nurturing and enjoyable.*
- *Carers often feel quite isolated. The opportunity for a drink and a chat can be very important. Perhaps the parish can set up an informal opportunity for carers to meet and chat over tea and coffee.*
- *Offer a lift on a Sunday or other times of the week. Members of the SVP, for example, can relieve carers through offering transport as well as support.*
- *Carers often feel a stigma in their role – encourage them to talk – and pray – about their experiences.*

