Care Alliance Ireland

Summary of Irish Field Work

life after care

Education and Culture
Lifelong Learning Programme

This project has been funded with support from the European Commission.

More about the Life After Care project on:

www.lifeaftercare.eu

Background

As part of Care Alliance Ireland's commitment to the Grundtvig Life After Care Project, and specifically to inform our understanding of post caring and to inform the contents of a booklet for former carers, we invited former carers to meet up and share their thoughts and experiences of the period post caring by way of a professionally facilitated and digitally recorded focus group in the centre of Ireland.(Athlone) This focus group took place on February 23rd 2010 and involved 14 former Family Carers.

Others in attendance included 2 staff from Care Alliance Ireland as well as a researcher from Trinity College Dublin who had just begun undertaking a primary piece of qualitative research looking at the experiences of Family Carers after their caring at home has ceased. The latter negotiated access to the focus group as it was considered helpful to her in identifying themes for her research. She was also allowed to invite participants to meet with her separately to be interviewed as part of her research project. Her specific research, when completed in December 2010, will also help inform the contents of the booklet.

In addition, 6 Former Carers will be taking part in the Dublin meeting in October 2010. It is envisaged that their input will also help inform the contents of the booklet.

Focus Group Meeting – Feb 24th 2010

Participants for the focus group were recruited in two ways;

i) Member organisation of Care Alliance Ireland were sent a letter inviting the to identify suitable participants. 14 participants were sourced this way

ii) Local print media were sent an article requesting that they please the article in their respective paper. 8 participants were sources this way

(See Appendixes I,II,III,IV)

Of the 22 confirmed attendees 14 turned up on the day with others sending their apologies.

A draft agenda was circulated to all participants in advance of the day. (See Appendix V) The inclusion criteria for the focus group were the following;

- (Ideally) The person will have ceased caring within the last 2 years.
- Happy to discuss their experience of caring and post caring
- Willing to interact with others
- May be involved with volunteering within a caring organisation
- Can commit to being available in Athlone on February 23rd 2010
- Would be willing to consider further involvement in the project by way of a 3 day visit to the UK in May 2010.

The focus group was in essence a listening exercise and in total there was in the region of 3 hours facilitated session (excluding breaks) The session was fully transcribed professionally.

The themes emerging are outlined below. However, in light of the limited depth and duration of the session, it would not be appropriate to generalise the observations to all former carers.

Summary

- The focus group was a powerful and emotional process for all involved.
- It was unfortunate that a small number (c3) of participants were current carers, contrary to the inclusion criteria. The facilitator decided not to look for these people to leave the session.
- The group seemed to find it somewhat difficult to focus on the post-caring issues, and had a clear need to verbalise their caring experiences. It seems that for some it was their first time to do so in a group setting. The session was arguably therapeutic and maybe even cathartic for some participants.
- The session did generate many stories and quotes that may be useful to include in the booklet.
- Little material was generated regarding the issues of re-integration into the labour market and or training. Some of the participants were either over 65 or approaching retirement age. On reflection, it may have been wiser to secure a younger co-hort of participants.
- Having said that, a number of participants were currently volunteering in their community in various ways, and some specifically either working or volunteering in carers organisations.

Details of Focus group Feedback Feb 24th 2010

- It appeared quite difficult to keep the group focussed on post-caring. They seemed to need to talk a lot about their caring. This was considered acceptable as to deny the opportunity to the participants to share their story would have been ethically questionable.
- In spite of thorough filtering of potential participants, it became apparent early on that 2 participants were in fact still caring. The facilitator reminded the participants of the criteria for inclusion - namely 2 years post caring.
- The issue of loss emerged throughout the focus group. Other feelings emerging regularly included guilt and loneliness.
- Several participants painted a picture of caring for several family members over a lengthy period of time.

Some verbatim quotes are presented below to give a picture of the themes that emerged;

(Text in italics indicates facilitator's voice)

Facilitator's Introduction

'the purpose of today is really to be a listening exercise. .. to spend time listening to carers' experiences so today is really going to be about you talking and me trying to help that along and capture, stitch up some stuff and there'll be notes taken as well, it's really about trying to capture that and have your experiences shape what might improve hopefully for carers in the future.'

'We want to talk about what your after caring experience has been like and this might be where it gets a bit tricky because we might find ourselves drifting back to talk about your caring experience but we really want to try and capture the after caring experience because that's really the specific focus, so it's really been divided roughly into what that experience is like for you and then in the afternoon looking at maybe taking a slight step back and saying okay what lessons have we learnt, what suggestions might there be for others going down the same route. Is that okay, is that making sense so far?'

'if you wouldn't mind start with saying who you are and where you're from and just say a little bit about your caring experience and I suppose in particular who was it that you were caring for, parents/siblings and what the condition was. How long were you a carer and when did the caring coming to an end, if that's okay.'

Participants Introductions – Their Stories of Caring

'I have actually been caring for eighteen years for my elderly parents. One had a stroke and the other had (unclear). My mum actually died three years ago (unclear) it actually was heartache, I was mourning and all sorts and my dad has actually passed away. '

'I was a carer for twenty four years and about two months… (unclear)… brain haemorrhage (unclear)'

'I'm a member of the Carer's Association (NGO) and I've been a carer since I was twelve for my Mam and Dad and I had back surgery (unclear) and my mother had her hip replaced, one of them (unclear). She died (unclear) brain tumour. Mam died in 1998. Then my father broke his hip in January of 1998 (unclear) and in August 2000 my Dad developed a major stroke which left him completely paralyzed. I had total care of him 24 hours, nothing could have prepared me for the void that (unclear), nothing, if I had been in prison or jail for twenty five years before I would be released from jail I would get all sorts of financial support, emotional support, everything but when you cease becoming a carer your let go totally. Dad died in January of last year and (unclear)…I've been a carer now for twenty five years, full time for twenty five years. Thank you'

‘I got married in 1982 to an only son who had elderly parents (unclear) so his mother had a psychiatric history and was very difficult and his father was getting very elderly so I was… in 1991 my husband’s father died very suddenly so we (unclear) with his mother until she died in 1999. She had medical problems, a big … psychiatric history and also dealt with that and on top of that then my husband had a single aunt and uncle from his father’s family so in the farming background …fell onto his shoulder… so they were aging and fell into that circle as well. So the Uncle died in 1996 and that left then the Aunt, my husband’s Aunt, who, once again, she was fine until she started to have the falls and all that went along with that and she died about three years ago, so ongoing there was four people there who I was running in and out through different cycles of life with and my own parents then, because they lived down the Country, my father, he has bowel problems and poor circulation and as a result became very depressed so my mother down South was left to carry that because I was just glancing in and out because I had all this at home and now at this point in time my mother’s going into that age bracket, so thank God I am in a situation now that when one of these people passed on I was nursing initially just as my training and then got married and had to stay at home to do that work, I had no choice and it just worked out.’

‘I cared for my mother, very hard to pinpoint, I suppose fourteen years ago she would have started (unclear) so really at that stage caring would have started. In 2004 to 2006 (unclear)… only for three months when she was quite good. My mother would have suffered from severe arthritis (unclear)… that really was full time care and (unclear). Fourteen years ago.

‘I had to nurse my first husband for about three years before he died and then my second husband for eight years when we got married. So my first husband was a late diabetic with hypertension and eventually his heart burst open completely, lost the water and all that kind of thing and a late diabetic (unclear) and my second husband had a hip operation just before we got married and the marriage had been arranged and postponed between one thing and another and he got MRSA in Merlins Park and he ended up with a lung condition, a heart condition and arthritis, osteoporosis and everything, asthmatic, he was on chemotherapy and he was on more medication than you can imagine and then he ended up on crutches.We had been dancing twice a week before he had the hip operation and he never danced again and he never walked without crutches again. He tried a few times on sticks but he never got there. He always had pain for the rest of his life, the eight years.’

‘I cared for my Mam from the time I was twelve. The onus was one me as my Mam would be in and out of hospital with various problems but she had a long term osteomellitis – an infection in the bone in her leg which flared up and over the years she would have various operations for kidneys and hips and various things so she would have spent a lot of time in and out of hospital and she lived with me and I had surgery myself two years ago and then I suffered a breakdown and at that time in the middle of the breakdown I was given an ultimatum that I either would look after Mam or my sister would but I had to decision and I wasn’t able to continue looking after her so I don’t look after her anymore and that’s two years ago, so I’m just picking up the pieces. My Mam’s still alive so I visit her and that.’

‘my Mum died three years ago from Alzheimers. I was looking after her for eight years from the time she was diagnosed with it and from the build up before that’.

‘I’ve been looking after my Dad for eight years. He has Parkinson’s disease and he had a heart attack and a stroke and he had cancer of the bowel and he had a colostomy bag, and he died in 2007. I looked after Mum for the same amount of time. She took a very bad depression and she had a stroke and then about three years later she had Alzheimers. She started (unclear). My Mum died in 2008.

‘I suppose nearly three years ago my father had colostomy bowel and at the time he was given three months to live but he actually lived three years and then ten years ago my Mam then came to live with us and she would have suffered with depression but I suppose about four years ago then she got a stroke and when she got the stroke the hospital at the time wouldn’t allow her back home to me so they insisted she had to go into care so then she did go into care and she broke her hip then in January two years ago and she would have been eighty six and when she broke her hip they said she was in hospital she was kind of more or less at the beginning of the end but I suppose I do think it is a miracle because she got the opportunity of coming back and she was inhospital so we would have gone to see her every day.

‘I looked after my husband for about thirteen/fourteen years. He was waiting for a heart bypass and he was ill while he was waiting for that and he was waiting for years and thirteen months after that he had a massive stroke. He was in hospital for five months and they wouldn’t let him home but I did get him home and he was in the bed with me and he had another massive stroke (unclear) and he died in January 2009. I can’t think of much after that really. I’m the daughter and I used to come over on holiday (unclear) after he had the main stroke and there wasn’t much (unclear) in a room downstairs (unclear section)…. But my mother started getting really ill she had osteoarthritis (unclear) so I gave up my job and my home and came over to help. My father was just, you had to feed him, my mother had to wash him down and (unclear). My mum has never been the same (unclear) so now I look after my mother now.’

‘I’m a member of The Carer’s Association (NGO) and I looked after my Mum until eleven weeks ago from about early 2005. She was a very fit lady and at about eighty five years of age she fell one day and shattered one hip and from that she was on a zimmer frame so I was looking after her. I was fortunate only to be working part time but the job I worked in I couldn’t get time out because I was a market researcher but I had been a (unclear) in a past life so I was working two or three part time jobs so (unclear) and her kidneys were failing a wee bit through age (unclear) and they diagnosed that her kidneys would deteriorate with age as she had a slight disfunction in her kidneys and she was pretty independent so things like toilet (unclear) and I was blessed to have a great carer (unclear) and I’m one of three so my sister (unclear section) … I didn’t want much because I was used to working long hours as a bartender in my young days so what happened was I used to just take Saturday night off from six and Tuesday night from seven and I was happy then of the respite which we did get … but about the 4th of December last (unclear) because she got pneumonia a few times (unclear)… so we tried to get her into hospital, got her into hospital and we discovered internal bleeding (unclear) …the next morning anyway to cut a long story short ….she had a minor heart attack but anyways to get away from all that she improved an awful lot (totally inaudible section)… She lived until about 10.00 a.m. on the 2nd of January (unclear).’

‘Having listened to everybody I’m not sure if I should even be here. I looked after my mother say for the last twenty years but I never seen myself as a carer I was always there for anything she wanted you know. It was only in the last three years, Mary my younger daughter because bed bound and she needed twenty four hours, seven days a week. Mary was always a chronic asthmatic eventually diabetes, severe anxiety, depression and so forth but at the end of the day when you step forward and say you're going to do this you get very little help and your family don't you know…but you're going to do all you can for your daughter (unclear) so when you make a stand you stand on your own, you get very little help in my experience. That might not be everyone's experience but you do your best and the range of emotions that you go through then, your on your own through them as well.

That man there ..(other participant) who thought he was in prison, sometimes you could be looking out the window and you might as well be in prison because you can't leave even with poor Mary, God love her, you couldn't leave her on her own even to go to the shops and the shop's only from here to there and she'd be like are you coming back, don't be long and you'd only be sitting in the room beside her. You had to bring the bed down, the two of us slept in the bed you know. Just there you know. In reality nobody cares unless you do it yourself you know so. Mary passed away in December last year and people say well…she passed away at the weekend or Sunday night/Monday morning and she started talking and I just thought it was Alzheimers or something like that and I tried to get her to the doctor (unclear)… she had an infection and he said your best to deal with that you your own (unclear) and I just say oh that's the way it goes and your left there on your own.

Time after Caring

'He died in July 2007, 2 ½ years ago and since then I have mainly lived with grandchildren, particularly one of them who is, she's eighteen years of age with a mental ability of eight and she has light, brain damage has left her with a drag on her right hand side foot. That's about it.'

'I had to (make a) decision and I wasn't able to continue looking after her so I don't look after her anymore and that's two years ago, so I'm just picking up the pieces. My Mam's still alive so I visit her and that.'

'It was only my brother and myself but then she died May of last year and that was very difficult because in November she went into the hospital for an … well they didn't know at the time that she had a blockage but in hindsight, if we'd known, it was just awful to think from November to the 2nd of May what she suffered but she's at peace today. But I'm still a carer and also I now have the privilege of working on the Careline (Carers Association NGO) so I feel she has done a lot for me.'

'Your world, even though you were a carer, at the time and all the rest of it, that world is gone and your in no world because your life as a carer, that's gone and that was twenty four hours and (unclear) and you might get the carer's allowance for six weeks but after that then you get nothing (unclear) your thrown to one side, it's like see you, good luck, we don't care what you do. So that's it.'

‘I just want to say, when we… prayer was a big thing in helping me and even though I was suffering from a lot of hurt and depression and that I would go to church and actually I gave out to our Lord, I did get very mad at him and I think that is good because when everything else fails we can’t expect him to fix everything and we’re angry and I suppose for me there was a freedom of actually giving out to him where you couldn’t say things to your brothers or sisters, sometimes I did which didn’t … (laughter)… Maybe what might help, I suppose for me, even being here today is a wonderful thing… sharing and to realise that we all kind of go through the same. ‘

After Caring – What Helped?

- Respect from hospital
- Various Voluntary Carers and Older Peoples organisations
- Prayer – getting mad with God
- Neighbours and friends – talking to us and talking us through things. Telling us we had done our best
- Telling yourself that you did your best
- Have no regrets
- Don’t bottle yourself in a room – go for a walk – get fresh air
- Alzheimers – access to work scheme – a link into work
- Active retirement clubs – gets you our into clubs get exercise
- Feeling a peace of mind that you were the advocate for the person you were caring for – being a voice – fighting the battle

After Caring – What Supports Were Missing?

- Opportunity to give feedback to hospital after bereavement
- Better facilities at point of bereavement – a room for a wake
- Opportunity to hear other carers
- Information re the process for stopping the Carers Allowance
- A call from a public health nurse
- Some support used to come from Parish Priest
- More access to bereavement counselling that is anonymous
- Some kind of follow-up and / or recognition from the system, even a letter to say thank you. (Follow up needs to happen when you are ready)
- Some kind of support system for carer during caring that prepares people for changes to come and them through current situation
- Outreach in shopping centres etc by carers organisations
- Website access info, correspond with other caters
- Better organisation of taking back equipment

Re-entering the labour market;

‘when John’s mum passed on in 1999 I returned to nursing, to work, so I chose to do that because I had to get some sort of balance on your life and I went actually into care of the elderly because there’s so many areas there, you now, I did the course covering general care of the elderly but I went to the care of the elderly which I felt just, looking at it from the other angle was just another picture so I’m still there nursing and in my mother’s situation now when she needs just little (unclear) and things, I can just kick in at the right time …. I can just programme myself home now with my brother you just know exactly when to kick in now, when to pop in and you get so much better for everybody, mum isn’t a problem at home now because I can just kick in ahead of … you see exactly what you’re in to. So that’s where I am now’

After Caring What Was Most Difficult- and feelings associated with

- Loss – including financial
- Guilt
- Loneliness
- Isolation
- Ability to cope
- Still on duty, have that responsibility
- That empty chair
- Loss of companionship
- Miss their voice calling your name
- Feeling still on duty
- Anger – with the whole lot
- Loss of purpose – what are you going to do now?
- Abuse from family if you have to give up
- Asking for help – should be in a home
- Very little support from siblings (after)
- If you do talk – shouldn’t have done it on your own “you got the house – they’re your problem”
- Hard to accept loss, feel you could have done more even if you know you couldn’t (need the lotto)
- Lost a friend
- Hard to deal with emotions
- Hold back in case you can’t stop
- No help / support from hospital when Dad died
- Sudden death is a huge shock, no preparation
- Guilt and relief
- Lots of difficulty at point of bereavement
- Way that someone dies, loss of dignity, pain relief

Feelings after the caring has ceased.

‘Guilt, terrible guilt.’

‘Maybe we should have done more. You beat yourself up.’
‘Loneliness.’

‘Isolation, total isolation.’

‘Inability to cope.’

‘Your not able to stop there and then, your kind of subconsciously still on guard or whatever.’

‘Still on duty …’

‘Your still on duty! You still feel you have that responsibility and you still kind of hop up and do another little thing that doesn’t need to be done anymore.’

‘That empty chair.’

‘Companionship.’ (*Not having it?)* ‘Not having it yeah.’

‘You miss the person calling your name.’

‘You still hear it.’

‘Yes, you imagine them calling you or talking to you or sometimes you look around quick to see if their back in their chair. You’re in the kitchen doing something and you look around quick.’

‘You feel you’re still on duty even though their gone.’

‘You feel anger.’

‘It’s very hard to accept your loss with the fact that you feel at times that you could have done more yet you know in your heart and soul you did all you knew you could do.’

‘When my Dad died I lost a friend.’

‘I found it hard when Dad died, he very suddenly took a heart attack … he was just gone’

‘I had very peculiar mixed emotions when my parents died. I missed them obviously, I had an awful sense of guilt that I felt relief. It’s the most peculiar feeling, I always said I missed them but it’s as if there was some weight lifted off my shoulders and I felt guilty over that, but what I was told was that I did my mourning when my parents were alive so that kind of helped me rationalise it, but I mean complete contradictions, guilt and relief.

Can I have everyone's attention and we're going to get back to work, okay. Right, what we're going to do now for the afternoon. I want to spend a little bit, maybe give it 20 minutes or thereabouts to focus on the slightly more positive side of ... and the aftercare experience. What things, is there anything else you've found has helped? What supports were missing that you'd really like to see in place or suggestions that you might have for what would help, okay? So we're going to give 20 minutes on that before we move on to our final session. I have to say that we are trying to keep it to the positive side of the coin now if that's alright because it's another aspect of the learning that's important to bring into the project. What has helped and what would help if it was there?

'What our group found was that our neighbours and friends talking to us and talking us through things helped an awful lot.' (*So neighbours and friends?)* Because they tried to impress on us that we should receive solace from the fact that we had done our best for the person we were caring for….. they are nearly better than family. (neighbours and friends)

'We should tell ourselves that, that we done our best.'

'Don't lock yourself up in a room, go out and have a walk, breathe God's fresh air, it helps you.'

What helped you?

'For me personally it was the Carer's Association….particularly Careline. (Free Phone Line Support Service)

'the retirement club gets you out an about, gets you playing bowls, gets you into exercise, gets you into core groups because when your caring the weight piles on from getting no exercise because you can't get out. You feel better then when you get to go out with other people in the same situation. That's all we had in our group.'

Okay, anything else that helped?

'I would think maybe peace of mind that I find that when your caring for the elderly you are advocating for them….so I got great satisfaction out of that. ' (*So getting peace of mind from saying that you were the advocate for the person you were minding.?)* That's right… to be their voice, because you just get pushed into the system so quickly. … that would have given me satisfaction you know.'

Support for Former Carers;

- Health Care Professionals
- Religious
- Bereavement Counselling
- Keeping Busy with other Things

‘It would have been nice if the public health nurses had called to see me to find out how I’m keeping, small things.’

‘I suppose it’s the whole thing that all services are for the cared for person and there isn’t real recognition of the carer having any needs at all in the system lets say.’

‘They say that the public nurses are supposed to call to all people over 70 every four weeks and no-one has called to me in the last year to my knowledge. ‘

‘The Priests used to call to houses to people as well and they don’t call anymore either.’

‘If a Priest called it’s to try and convert me, he has his work cut out! ‘

‘In our parish we had bereavement counselling which would be associated with the church. ‘

It’s in our parish as well but I find that I wouldn’t like to go to a parish, you know what I mean, not that I, I’d just like to go outside the parish. I know it’s all supposed to be confidential but I …

‘You’d prefer to talk to a stranger.’

‘Just somebody to listen.’

‘I was in the parish but I went (to counselling) outside.’

‘but getting back to the health thing there is a communication break down you know there are so many (unclear)… when somebody passes on, I’ve found, because I was part of the furniture really, as somebody who was trying to juggle work ….I really wasn’t able to face the world (unclear)… but when I went back at Christmas (unclear)… it was about 3 o’clock and I was having a cup of tea, but I didn’t see any nurses (unclear)… and nobody (unclear) and I couldn’t see a chair so I’m standing there and I didn’t mind that and then they brought around tea and they didn’t even ask if I wanted a cup of tea. Nobody even asked me how, you know, nothing, and I had very close connections with them I was always writing letters for them and things (unclear)… and just I was abandoned after, you know, and even a social worker who was recently in touch with and I was on different committee meetings with her and she should have known (unclear). I rang her (unclear) but she never rang me afterwards to see how I was coping and how I was getting on you know.’

So it’s very lax then, and it only takes two minutes.

‘It’s just a job.’(for the health professionals)

‘Breakdowns in communication all over.… There is just nothing you know and when you ring someone afterward you just walk away and nobody ever asks you anything, you know, they never ask you.’

So some kind of follow up from the system.

‘Or even if they rang you but they never come in…’

‘because the only thing that I got or would ever get and I was a little bit surprised that I got it was on the bereavement grant it says deepest sympathy. That’s the only thing you get from the State. Everything else is just send back the card, send back the equipment, your finished now get lost. That’s all your going to get is that little bit and even that you appreciate. But that’s all you get.’

‘Then you have to go through the rigmarole of getting a death certificate.’

‘An outreach, absolutely and they need to be hiring their local credit union and they could be a volunteer, I mean you don’t have to be, you’ll be briefed on what the organisation has to offer, but look at, in your local credit union, a half an hour could mean such a difference to one person.’

‘Well I was just thinking because computers now have become so available that maybe it would be worth having a site where people could if they were used to a computer, could go in an maybe correspond with another carer who had been in the same situation. I’m not into computers so I won’t be on it’

What advice would you give to a current carer?

- Communicate
- Inform people of their entitlements
- Respite
- Carer mind self
- Don’t ask – will not receive
- Watch short term fixes – i.e. drinking
- Depression – Awareness of
- Ask for help and delegate more and done be ashamed to ask for help
- Don’t be ashamed to show your emotions
- Value your own health
- If you think about yourself, your not being selfish
- Document all financial dealings
- Consider your own family commitments resulting with short falls and needs

Advice for former Carers;

- “Let go of the guilt”
- ‘I haven’t really any guilt because I did all I could for my mum so you know, I hadn’t any guilt. A lot of people had. It all depends on your own experience you know, so that’s why we had the question mark.’
- Get out of the house, and keep your mind active
- Let go of the guilt and value oneself more
- Try to get your life back
- Join some organisation
- Take satisfaction in your years of caring
- Good well balanced information and website for carers
- Try not to feel guilty
- Don’t expect life to return to normal
- Be good to yourself

What did you learn from your caring experience?

- Patience
- Love
- Respect
- To feel valued
- Recognise own need
- To appreciate your own health
- Necessity of respite
- To value life
- Role reversal
- That you are on your own

- To tell family your needs
- You got love and satisfaction in return
- Acquired new skills
- ‘In our individual cases we are the experts’
- It’s lovely to return the love to our loved ones

General Statements/Quotes

‘Well what was normal was caring for a loved one so how can you return to something that’s already gone?’

- ‘If you were in a hospice and had cancer you would be treated properly’

Appendix I – Letter sent to Care Alliance Member Organisations (NGO's)

Dear ,

Re : The Post Caring Needs of Family Carers.

We in Care Alliance Ireland are delighted to be part of an EU project that is looking at the needs of Family Carers after their caring has ended. Specifically we are looking for a number of people who have ceased caring within **the last 2 years** to meet up together in the **Radisson SAS Hotel, Athlone on Tuesday February 23rd.**
Participants will need to be willing to share their thoughts and experiences of the period post caring with the group, which will be facilitated by Sheila Cahill, an experienced facilitator. The day will begin at 11am in Athlone and end at 4pm. All reasonable travel expenses incurred will be reimbursed and lunch will be served. This will be the extent of the commitment required.

Inclusion criteria include;

- (Ideally) The person will have ceased caring within the last 2 years.
- Happy to discuss their experience of caring and post caring
- Willing to interact with others
- May be involved with volunteering within a caring organisation
- Can commit to being available on February 23rd 2010
- Would be willing to consider further involvement in the project by way of a 3 day visit to the UK in April/May 2010.

An additional part of the Life After Care Project will involve approximately 4 'post-carers' travelling to London in April / May 2010 for 3 days to meet with people from the UK who have also recently ceased caring. Participants at the Athlone meeting will be invited to consider applying to partake in the visit to the UK. Again all costs will be covered for this visit.

I am including fliers and registration forms that you may choose to copy and distribute to potential participants by **Monday January 25th 2010.** I would be delighted to discuss any aspects of the project with you. You can contact me on 01-874 7776 or by email info@carealliance.ie

Further details of the Life After Care project can be found at www.lifeaftercare.eu.
Yours sincerely,

Esther Kavanagh

Esther Kavanagh, Care Alliance Ireland
Encl.

Appendix II - Flyer/Poster – used to Recruit Participants for Focus Group

Have you recently stopped caring for a Family Member/Friend?
How did you feel after your caring role ended?
Were you adequately supported by friends, family, the state?
Would you like to help us understand this post-caring' time in your life and help improve services for ex-carers?

Would you be available to meet up in The Radisson Hotel, Athlone on Tuesday February 23rd from 11am -4pm for a day with other ex-carers?

(All expenses will be covered)

If you are interested please contact Esther on 01 874 7776 by January 30th 2010.

This project is part of the EU Life After Care Project. For further details see www.lifeaftercare.eu

Appendix III – Registration Form for Participants

Life After Care Registration Form
Radisson SAS Hotel Athlone,
Tuesday February 23rd 2010

(PLEASE COMPLETE IN BLOCK CAPITALS)

Name: ____

Postal Address:____

____

Email: ____

If you have special communication, access or dietary requirements for the seminar please specify here:

____

Please send the completed registration form to Esther Kavanagh,
Care Alliance Ireland, Coleraine House, Coleraine Street, Dublin 7.
Enquiries to Esther on 01 874 7776

Places are limited so early booking is advisable
Closing date for registration is Monday 8th February 2010.

Appendix IV – Confirmation Letter

Address

Date

Dear (first name)

Thank you for registering to come to the "Life After Care" Seminar which is being held at the Radisson SAS Hotel in Athlone from 10am-4pm on Tuesday February 23rd 2010.

We are delighted that there has been so much interest as we feel that this is a very important issue. So that you will be aware of what is happening during the seminar I have attached a schedule outlining the programme of the day. We have tried to include time for you to talk, share experiences and also for you to enjoy the day as much as possible.

Your willingness to travel and to participate in this seminar is greatly appreciated, and as we had stated, travel costs will be reimbursed so may we ask that you please bring any travel receipts (such as bus/train tickets) with you to enable us to reimburse you for these costs. Unfortunately we will not be able to make payments without receipts. For people driving to Athlone we will reimburse your travel costs at a fixed mileage rate.

If your circumstances have changed and you are unable to attend I would ask that you let me know by contacting me either by email at info@carealliance.ie, phone at 086 883 4942 or writing to me at
Care Alliance Ireland,
Coleraine House, Coleraine Street, Dublin 7.

We look forward to meeting you on the day

Yours Sincerely

Esther Kavanagh
Care Alliance Ireland

Encl.

Appendix V - Draft Agenda for Focus Group Meeting

life after care

Athlone – Life After Care Seminar
Schedule of Day

10am-11am – Arrival – Registration – Tea/Coffee, Scones

11am - Welcomes –Liam O'Sullivan, Executive Director, Care Alliance Ireland

11.05am - Background to the Project – Esther Kavanagh, Administrator, Care Alliance Ireland

11.15– Session 1 - Sheila Cahill, Facilitator, including introductions by participants

12.45pm- 1.45pm Lunch

1.45 – Session 2 - Sheila Cahill

3.30 – Review

4pm – Finish Up

Care Alliance Ireland is a company limited by guarantee not having a share capital, registered in Dublin, Ireland, with registered office at:

Coleraine House, Coleraine Street, Dublin 7
www.carealliance.ie Telephone: (01) 8747776 E-mail: info@carealliance.ie
Registered Company No: 461315 CHY No: 14644

Directors : G Clarke, C Conway, J Day, Dr. G Fennell, F Goodwin, A Kavanagh, C Keogh, Dr. P Lane, M Lynch, R Webster.
Patron: Dr. Maeve Hillery

Appendix VI

Who Cared For	Condition	How Long	When Ended
Parents	Stroke / Arthritis	18 yrs	3 years
Husband	Brain Haemorrage/ Stomach Closed / Ulcer – colitis	24 years	1 ½ years
Mother / Father	Brain Tumour/ Broken Hip/ Stroke – paralysed	Since age 12 (25 year full time)	1 year
Mother in law/ Father in law / Uncle – Aunt in Law / Mother / Father	Pschyiatric Illness / Aging / Falls/ Bowel Problems	1986-2007	3 years
Mother	Osteoarthritis	14 years	10 weeks
Husband 1 / Husband 2	Diabetic – Hypertension / MRSA – Lung Heart condition – Asthma	3 yrs / 8 ½ years	2 ½ years
Mother	Osteomelitis	From age 12	2 years
Mother	Alzheimers	8 years	2 years
Father/ Mother	Parkinsons – Heart Attack – Stroke – Cancer of Bowel / Depression – Stroke - Alzheimers	8 Years / 8 Years	3 years / 2 years
Father / Mother	Colostomy / Depression – Stroke – Broken Hip	10 years	8 months
Husband / Father	Heart Condition – Stroke	13-14 years	1 year
Mother	Fall – Broken Knee – Kidney Problems	5 years	11 weeks
Mother	Bed Bound – Asthmatic	20 years	2 months