Caring for older carers: Recognition, celebration, and support

‘Bear one another’s burdens and so fulfil the law of Christ’ Galatians 6:2

I didn’t know YOU cared!

Since 2001 the National Census has asked people to report the amount of time they give to looking after, helping or supporting family members, friends or neighbours because of ‘long term physical or mental ill-health or disability or problems related to old age’. The results have revealed the extent of informal unpaid care that takes place in the UK, and that a disproportionate amount of this care is provided by people over 65. Around 15% of over-65s give a significant amount of care, and older carers are likely to be giving more hours of care per week than their younger counterparts. In fact, as age increases the amount of care provided rises; across the UK there are about 8,000 people aged over 90 who provide more than 50 hours of unpaid care per week.

This may surprise us, because when we think about care in relation to older people, we tend to think of care given to older people, not care given by older people.

Of course many older carers are caring for other older people. The most common scenario is an older person caring for an even older parent, or an older person caring for a spouse who may be somewhat older. However, older people may also care for adult children with special needs, such as mental or physical disability or severe mental health problems. Older people may also be involved in the care of grandchildren, even being the primary carers in the context of family breakdown. (Grandparents – many of whom are in the younger 45-65 age group - are the main providers of child care for about one third of families where the mother is working or studying.)

Many of these older carers are retired, but many continue in some sort of paid employment alongside their caregiving commitments. Equal numbers of men and women take on these roles; women predominate in the 65-75 age group, but the majority of very old carers are men.

This massive group of people is largely invisible. Indeed, a recent Age-UK campaign for greater recognition of older people who give care was entitled ‘Invisible but Invaluable’. The invaluable bit is important: these people save the nation millions of pounds through their unpaid service, and by the worrying fact that older carers tend not to take up all the monetary


2 Stanham, J. (2011). Grandparents providing child care. Institute of Education, University of London; Loughborough University; Personal Social Services Research Unit, University of Kent.


4 http://www.ageuk.org.uk/get-involved/campaign/older-carers/
benefits to which they are entitled. They are also a source of enormous ‘social capital’, sustaining an ethos of care in local communities.

What do we mean by ‘caring’?

‘Caring’ covers a wide range of activities. It may involve hands-on physical care, offering practical help with the tasks of life, or being a source of emotional support. It may mean that you are identified as the one who cares about that person, steps in when things go wrong, or takes overall responsibility – feeling that the buck stops with you.

Patterns of caring relationships are very diverse. They may be continuous or sporadic – responding to need. They may be routine, or focused around crisis. They involve making oneself available physically or emotionally - often both. So, caring is highly demanding.

Issues for older carers

- Finances: Older carers are living off pensions. Claiming the benefits to which carers are entitled involves understanding a complex and changing system, and much of the relevant information is available on the internet. Older people may not have computer skills or access to the internet.
- Identity: Older carers often do not identify with the word ‘carer’. They see what they are doing as a natural part of their relationship. (This is one reason for the low take up of benefits.)
- Vocation: Older carers often take great pride in caring for a loved one, enabling him/her to remain in familiar and comfortable surroundings, and in their turn to receive love and companionship.
- Health: About 50% of older carers are themselves coping with a limiting long term illness. Caregiving itself can cause stress, depression, and exhaustion, and carers often do not have time to take part in health-giving activities.
- Social isolation: Carers can have difficulty taking a break from the caring role because of unavailability of respite services, or guilt and worry at leaving their loved one. For older carers and those in rural settings transport can be a particular problem.
- Lack of recognition: Sometimes carers may collude with this in order to protect their loved-one from stigma, for instance covering up for someone who is in the early stages of dementia.
- Mourning: There can be silent grief for someone they used to know who is no longer fully present to them, or not present at all; or grieving for someone for whom they perhaps had different hopes
- Abuse: It is all too easy for relationships of care to develop into emotionally or even physically abusive patterns. Carers can be abused and they can also abuse.
- Fear: Older carers fear that their own health may deteriorate so that they will not continue to be able to care for their loved ones; they fear what will happen to their loved ones after their death; and

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11 If you have any concerns about the safeguarding of a vulnerable adult, please see http://www.oxford.anglican.org/pcc-and-dcc-support/safeguarding/

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Take up is only about 10% (based on figures from the Department of Work and Pensions 2005 and the Northern Ireland Statistics and Research Agency 2003).


Age UK survey, 2010.
a difficulty in ‘letting go’ (especially adult children with special needs).

- **Expertise**: Carers hold a good deal of expert knowledge about those in their care, but this is not always given due recognition and weight by professionals.
- **Spirituality**: The opportunity for carers to exercise a ministry outside of their caring role is likely to be restricted. Carers have spiritual needs of their own, including the need to attend public worship or informal fellowship groups, which often go unmet. Particular spiritual issues that arise in the context of caring include:
  - Being honest
  - Dealing with feelings of guilt
  - Giving and receiving forgiveness in the relationship
  - Finding a space to be oneself
  - Exploring caring as vocation or worship
  - Learning to receive from others
  - Learning to let go

**What can churches do? 1. Recognition**

- The first thing is to be attentive to the caregivers with whom we come in contact: to notice those who accompany people with any sort of special needs to church, to notice others who are in the house when we take someone home communion.

- More formal recognition can be given to these people by mentioning them (by name with their permission) in intercessions, not simply praying for the sick and distressed, but those who give them care, paid and unpaid.

- Consider organising service or event to celebrate the contribution made by caregivers. Some suggestions for putting such a service together are given in the second part of this resource sheet.

**What can churches do? 2. Connection**

- Consider holding a midweek service, fellowship group, or church meeting in the home of a carer, and providing a volunteer to sit with the person who is cared for if necessary.

- A lunch club or coffee morning for older carers (but probably not using the term ‘carer’!), where they are served, and care is also provided for their loved ones is a more ambitious idea. A short act of worship or simple reflection could be incorporated. This sort of enterprise would be labour intensive. Transport is also likely to be an issue, and could be helped by a partnership with an organisation such as Age UK.

- It is important to see people as more than carers or receivers of care. Consider inviting an older carer to address a meeting on some aspect of life or ministry in which they have gifts, experience, and wisdom.

**What can churches do? 3. Providing information**

There are many organisations – faith based and secular – that provide information that may be of help to carers and those for whom they care. Churches can act as information hubs, keeping a stock of leaflets, perhaps enabling access to internet information, or personally putting individuals in touch with those that might help them. Examples of some of these organisations:

**Age UK**
Has produced two really helpful booklets: ‘From us to you: Top tips for older carers from older carers’ and ‘Advice for carers: A practical guide’. Available from

[www.ageuk.org.uk](http://www.ageuk.org.uk)
0800 169 65 65

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Age UK Oxfordshire
The local, and very active, branch of AgeUK

www.ageconcernoxon.org.uk
01235 849400

Alzheimer’s Society

www.alzheimers.org.uk
Helpline 0945 300 0336

Carers UK
Information and advice for carers of all ages

www.carersuk.org
020 7378 4999

Carers Oxfordshire
Provide an emergency carers support service

carersoxfordshire@oxfordshire.gov.uk
0845 050 7666

Guideposts
Independent living resources for people with dementia, mental health problems or learning disabilities (based in Witney)

www.guidepoststrust.org.uk
01993 899980

Oxfordshire family support network
Has started a network for older carers of adults with learning disabilities

www.oxfdn.co.uk
01865 369477

Princess Royal Trust for Carers
Information and advice for carers of all ages

www.carers.org
0844 800 4361

Rethink
A mental health charity that offers support to family and carers

www.rethink.org
020 7840 3188

Short breaks for carers (Bucks)
Organise a carers’ breaks scheme

shortbreaksforcarers@buckscc.gov.uk
01296 387155

What can churches do? 4. Pastoral care

➢ Be proactive about asking what practical help is needed. Sometimes church members are willing to help, but nervous about what is required. A little bit of training may be all that is necessary. Don’t forget to involve your parish safeguarding officer if the task involves spending time alone with a vulnerable adult.

➢ Giving carers time and space is important:
  o To take a break
  o To be themselves
  o To express their worries, stresses, and joys honestly
  o To laugh and to cry

➢ Some key gospel truths that we all need to re-appropriate from time to time, but may be especially important for carers:
  o Even when things don’t seem to make much sense God is with us
  o We can face the future with hope
  o Whatever our daily work, paid or unpaid, it is a gift from God and also a gift that we offer back to God

A service of celebration and thanksgiving for caregivers

Planning the service

What are the aims?

There are likely to be several aims: acknowledging and celebrating the vocation of people who give care; educating the church and wider community about the largely invisible contribution of caregivers; setting aside a dedicated time for caregivers to worship unencumbered by their usual duties; offering a time of refreshment to caregivers, building informal support networks in the church and wider communities.

Who is it for?

You may want to have a service at which both the caregiver and cared-for feel comfortable. Alternatively (and this is easier) you might focus exclusively on the caregivers. However, even in this sort of service, the reciprocal nature of the caregiving relationship should be acknowledged. Carers often talk of the unexpected gifts they receive back through the caregiving process (though for some it can feel largely thankless, and the diversity of experience should also be recognised).

The service may primarily be for carers and/or cared-for. But if one of the aims is wider recognition of the people and issues involved, then a big service to which community representatives are invited is also a possibility, or the service might take the place of the usual main Sunday service.

Will it focus on a particular age group or condition?

You may want to have a general celebration of all forms of caregiving. Alternatively, you may wish to focus on a particular group of caregivers – young carers, older carers, or on a particular health condition such as dementia.

When is the best time to hold it?

This will depend on the needs of your group. For instance, if many of the cared-for attend day care or education centres, then a service that fits in with drop-off and pick-up times would work well. This is likely to be mid week between 11.00 and 2.00.
Every year there is a National Carers Week. In 2012 this is 18th - 23rd June www.carersweek.org. You may wish to make use of some of their materials and link your service with their activities.

**What support and resources are needed?**

Full time caregivers can have great difficulty in leaving home to attend any sort of community activity. They will need sufficient notice to make arrangements for cover. They should also be offered the opportunity to bring the cared-for person with them if appropriate. This will often have implications for transport. The service should be held in a building that is wheelchair accessible and with accessible toilets (this may rule out some churches). It is also important to have a place for individuals to sit if they are not taking part in the service, and enough helpers to spend time with them.

A social time – tea, coffee, lunch – after the service will require more human resources, but is likely to be an integral part of the event.

Having literature available from a range of organizations (for a list see page 4) is also a good idea.

**Who should be invited?**

Much caregiving is invisible. In addition to the usual way of advertising services, it is worth contacting the family members who reside with people in your parish who receive regular home communion, and leaving invitations in GP surgeries. (GPs have a responsibility to identify informal carers as part of the government’s carers’ strategy.14) Professional carers employed by local agencies or residential care facilities may also appreciate an invitation.

**How might it be followed up?**

Holding a one-off service may be the beginning of offering a more regular event for caregivers such as a coffee morning or lunch club: ask the participants what they would like. Cards could be made available for those who would like a home visit from clergy or a member of the pastoral team can leave their details.

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Basic Service Outline

Within this framework it is possible to be very flexible, including, music, poetry, personal stories etc.

PREPARATION

Welcome and opening prayer

THE LITURGY OF THE WORD

Bible reading (s)

Psalm or scriptural song

[If this service is replacing your usual main Sunday service then a sermon or reflection on the reading(s), and a creed or affirmation of faith should also be included.]

PRAYERS

Including a Collect and the Lord’s Prayer

[If this service is replacing your usual main Sunday service then Prayers of Penitence should also be included.]

ACTION

An act of commissioning
or Symbol of thanksgiving (giving a gift or card, lighting a candle,...) or Anointing [which should be administered only by a minister authorized for this ministry]
may take place at this point.

CONCLUSION

Blessing or peace or grace, and dismissal
An example of a simple weekday service in celebration of older caregivers

PREPARATION

Welcome and opening prayer

God of Love and Care who chose Abraham and Sarah to care for Isaac, and Zachariah and Elizabeth to care for John in their old age, whose servants Simeon and Anna watched for the fulfillment of your Kingdom and called down blessings on your son, we give you thanks for the tender love and service of all older people who give care. This is so often a quiet and private ministry but nothing is unseen by you. Give your church the eyes to see it, a heart to celebrate it, and hands ready to help. We ask this in the name of him who gave his life for us, your Son, Jesus Christ. Amen

Hymn or song

The Collect for the day

THE LITURGY OF THE WORD

First reading Isaiah 46:3,4

Second reading 2 Corinthians 1:1-5

Psalm 23 (Psalms 71 is also very appropriate)

Third reading 1 Corinthians 12:12-27

PRAYERS

These use the refrain

May we bear one another’s burdens and so fulfill the law of Christ
Father, forgive our blindness to the courage and wisdom of those among us who give care to their loved ones. Forgive our lack of imagination, forgive our tendency to act as individual organs and not as parts of an interconnected body. Confident in your forgiveness, May we

Bear one another’s burdens and so fulfill the law of Christ

We give thanks for all who work to support care-givers individually and through national campaigns particularly today thinking of the work of Age UK and Carers UK. May we

Bear one another’s burdens and so fulfill the law of Christ

We pray for those for whom we care, naming them in the quiet of our hearts…. Help us to entrust them to you. We give thanks for what they are able to give to us. We offer you our worries for the future. Make us ready to ask for help and support and give us grace to receive it. May we

Bear one another’s burdens and so fulfill the law of Christ

We pray for ourselves, for health and strength – physical, emotional, and spiritual. Help us to lean on you, give us others to share our load. Help us to be kind to ourselves, as you have been kind to us. Above all, keep a flame of hope burning in our hearts. May we

Bear one another’s burdens and so fulfill the law of Christ

We pray for your body, the Church. Bind us together in love that the fruits of your Spirit may flow through our lives; love, joy, peace, patience, kindness, goodness, faithfulness, gentleness, self-control.

Bear one another’s burdens and so fulfill the law of Christ

They conclude with the Lord’ Prayer

ANOINTING

Hymn or song

Those who wish, receive anointing on their palms as an act of healing and recognition of their vocation

CONCLUSION

Hymn or song

We say the Grace to each other:

The grace of our Lord Jesus Christ, and the love of God, and the fellowship of the Holy Spirit be with us all, evermore.
Amen.