

***Good Ideas* for day carers and respite carers who provide support to older people in their own homes**



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REPORT

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Authors:

Melanie Lewin, Heather Wilkinson and
Caroline Donaldson

The Royal Bank of Scotland Centre for the Older Person's Agenda
Queen Margaret University, Edinburgh, Musselburgh EH21 6UU
t. 0131 474 0000 f. 0131 474 0001 e. copa@qmu.ac.uk www.qmu.ac.uk/copa

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GOOD IDEAS

Authors: Melanie Lewin, Heather Wilkinson and Caroline Donaldson



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THE RESEARCH AND DEVELOPMENT TEAM

Research Team

- Melanie Lewin, City of Edinburgh Council Department of Health and Social Care
- Heather Wilkinson, Co-Director, RBS COPA
- Caroline Donaldson, Research Assistant, RBS COPA
- Maurice Ashbridge, Liz Taylor, Rena Johnston, Susan McLean¹

Project Advisory Group

- Fiona Borrowman, Programme Manager – Health in Later Life, NHS Scotland
- Marjory Thomson, Professional Adviser – Nutrition, The Scottish Commission for the Regulation of Care
- Bob Laventure, British Heart Foundation National Centre for Physical Activity and Health, Loughborough University
- Eileen McNaughton, Planning and Commissioning Officer – Older People, City of Edinburgh Council Department of Health and Social Care
- Anita Jeffries, Ageing Well Manager, Edinburgh
- Jenny Livingstone, Social Worker with the City of Edinburgh Council Short Breaks Team
- Maurice Ashbridge, Member of COPA Advisory Panel and COPA HUB

¹ A key element of the work of COPA is the involvement of older people. To this end, COPA has developed a HUB network comprising a mix of people with an interest in older people's issues. HUB Associates are members of this network; older people who work in partnership with COPA and are involved in COPA activities, such as research

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INTRODUCTION

This report provides information about the RBS Centre for the Older Person's Agenda 'Good Ideas' project which was carried out during 2008 – 2009. The aim of the project was to consider ways of supporting day and respite carers who are working with older people who are housebound and their families. The report complements and should be read alongside the booklet which was developed as a result of the project: *Good Ideas – a practical handbook for supporting older people in their own homes*, available from RBS Centre for the Older Person's Agenda, Queen Margaret University, Musselburgh, Edinburgh, EH21 6UU.

Telephone 0131 474 0000, e-mail copa@gmu.ac.uk

or downloadable from http://www.gmu.ac.uk/copa/publications/research_reports.htm



**Good Ideas Launch – March 2009
The Project Team**

SECTION 1:

Context

1.1 Housebound older people and their families

In common with other countries in the western world, Scotland has an ageing population. However, many older people are now being supported to remain in their own homes, rather than having to move into residential care as their needs increase. Although this is in line with the expressed wishes of older people - for whom moving into care often presents a daunting prospect - over time, extreme physical frailty may result in them becoming 'housebound' and isolated from the wider community. Relatives and friends who provide informal care may also find themselves trapped within the home.

There does not appear to be a commonly agreed definition of what constitutes the state of being 'housebound'. One study carried out by the think tank, Demos (Ref 1), suggests that the word 'housebound' has *'negative connotations, conjuring up images of helplessness and dependence'*. A survey carried out by the Joseph Rowntree Foundation in 2004 opted to consider people who were unable to leave the home without help as 'housebound' or, as a preferred title, 'restricted' (Ref 2). Although recognising its limitations, the term 'housebound' was retained for the *Good Ideas* project as, at least to date, it is in more common usage.

Perhaps resulting from the lack of a clear definition, there do not appear to be any readily accessible statistics on the numbers of people who can be considered 'housebound'. However, 2% of a sample of people over the age of 70 who were questioned as part of the Scottish Household Survey in 2006 said that they never go out / are housebound (Ref 3). It is predicted that the number of people in Scotland over the age of 65 will have risen from 787,000 in 2000 to 1,200,000 by 2027. If the above figures are correct, by 2027 around 20,000 older people in Scotland will be housebound.

1.2 Provision of support within the home to older people and to family carers.

Many people come to rely on care agencies to provide support as they grow older – depending on professional help with personal care, shopping, meal preparation, housework. Their families may come to rely on other services – such as residential respite units - to provide them with the breaks they need to enable them to continue caring.

There are other services which vary in model of delivery, are not as widely available and which are perhaps less well known. These include ‘outreach’ day services – regular day support provided within the person’s home for those who cannot access a day centre - and also home-based respite care (formerly called ‘sitter services’). Although provision of such services varies within the UK, one of the largest national sector providers of respite for informal carers – Crossroads (Ref 4) – has, according to their web site, 48 schemes in Scotland which provide around 1 million hours of short breaks (respite) per year to older people, disabled people and their families.

1.3 The need for services which provide short breaks and breaks from caring.

The need for and the value of services which offer short breaks for older people and their families was recognised in the Scottish Government’s report: *All our Futures: Planning for a Scotland with an Ageing Population: 2* (Ref 5) The report acknowledges the need for a range of health promotion activities to respond to the needs imposed by demographic changes in the population. These include the development of physical activity work programmes for older people, health improvement initiatives, raising awareness about the importance of a healthy diet, and giving older people ready access to relevant information. The report also states that in order to develop and provide the right services, the involvement of older people is essential.

The report recommended (2.3), an increase in the amount of short breaks provision, not only to provide relief to informal carers, but also as part of the ‘continuum of care provided to older people living in their own homes’. The report also advocated more personalized breaks.

The Scottish Government's guidance on respite (Ref 6), published in 2008, similarly advises local authorities of the benefits for both service users and informal carers of appropriate short breaks, delivered both within and outwith the home.

Stoltz et al (2004) (Ref 7) claim that *"in home respite care is the (by family carers) most wanted service and yet the service is not often granted as support to family carers"*.

1.4 The Edinburgh context

Live Well in Later Life, produced by the City of Edinburgh Council in partnership with NHS Lothian to address the changing needs of the local population, states that currently 28% of older people needing intensive health and support still live in their own homes and the Council aims to raise this proportion to 50%. The plan stated an intention to *"substantially extend the choices for the care and support of older people in Edinburgh over the next ten years."* (Ref 8)

A review of City-wide day services for older people carried out by City of Edinburgh Council in 2007 identified a need for *"home based services for people no longer able to use or benefit from centre based services"* and stated that *"a range of quality home based and centre based services ... will be available... in order to provide choice and to promote inclusion"*. (Ref 9)

SECTION 2:

How the project came about

2.1 The City of Edinburgh Council Short Breaks Team

The Short Breaks Team is a 'Shared Lives' service (Ref 10) within the City of Edinburgh Council. The Team recruit, assess, train and supervise 'community carers' who provide a range of personalised day and overnight support services across the City. The services include one to one day care support, outwith the service user's home or within the home, some of which provide regular respite breaks for family carers. The model allows the Team to provide individualised support, tailored to the needs and wishes of each older person and his or her family. For example, an older person with dementia goes for walks in the country once a week with his community carer, as an alternative to attending a buildings based day centre. A second community carer, a retired engineer, is 'matched' with an older person who was also an engineer and they enjoy joint visits to places of interest. One carer who speaks Spanish spends time with two older people for whom Spanish is their first language and who would find it difficult to manage in a day centre setting. Shared Lives services are very much based on the establishment of close, trusting relationships with someone with shared interests. The model ideally bring benefits to all involved – the person who needs the support, their informal carer, who is treated as an equal partner, and also to the community carer, who is able to work flexibly. All are supported by one of the Team's resource team workers.

The Short Breaks Team periodically invited other Edinburgh providers of outreach services to a meeting, to discuss common issues. One of these issues was the increasing number of older people being referred to services who were 'housebound' – able to leave their home only with difficulty, or unable to leave the home at all. Where the focus had previously been on assisting the older person to be able to go out and about, these organisations' carers were now being required to spend time with the older person within the home. If this time was primarily to give family carers a break – perhaps the only break they would receive during a seven day period – the time spent could or should last for several hours at a time. Whereas other types of care require the carer to undertake clear tasks – such as assisting with washing,

toileting, administering medication, preparing meals – providing outreach day care or respite care requires the carer to be with the older person, to provide company, to help them to maintain skills, or to help ensure their physical or mental well being. The carer's role could vary from week to week and from person to person, depending on the individual, his or her needs, and the needs of family carers.

Providing regular day support or respite within the home setting can therefore be challenging for carers. Unlike other types of service provision, they may have several hours to spend with each older person, but without the tasks being as clearly defined. The carer needs to be able to build on whatever resources present themselves, to respond sensitively and respectfully to the changing needs of the older person, and to be able to form trusting relationships – both with the older person and with his or her family carer. Such relationships may have to be sustained for a long time, until the older person moves into care, is admitted to hospital, or dies. Although they will have the support of their organisation, carers work on their own and, to be fully effective, have to make good use of the time they have available to spend with each older person they visit.

2.2 Project Aims

The group were successful in securing funding from RBS Centre for the Older Person's Agenda, NHS Health Scotland and City of Edinburgh Council to focus on the needs of carers who provide support to older people within the home. The one year project had the following aims:

- to review what is already known about the needs and wishes of older people who are housebound, from older people themselves.
- to explore and record what carers are currently doing when they visit older people at home and, in particular, to highlight examples of good practice.
- to develop, evaluate and share good ideas to support carers in their work.

Project Aims

Funders required the project to focus on three specific areas:

Social relationships, nutrition and physical activity. Staying fit and well is particularly challenging if you are frail, or are restricted to your own four walls. Retaining interest in food and healthy eating is similarly challenging if you always eat alone.

The research questions that the research team were interested in answering were:

- What would an older person who is housebound want or need from someone who is able to spend three or four hours with them that would help them maintain or develop their social relationships, help to make sure they are well fed and take enough fluids, and are helped to stay active?

- How can carers who are providing day services to older people in their own homes 'tap into' older people's own natural resilience and build on their own existing resources? What sorts of things do older people who are housebound do already to help themselves? What support would further help them to help themselves?

SECTION 3:

Project structure, methodology and implementation

3.1 Organisations and individuals involved

The Royal Bank of Scotland Centre for the Older Person's Agenda at Queen Margaret University is an established research and educational 'hub' promoting the involvement of older people. The Centre has carried out many research projects to promote the well being of older people, involving older people as researchers in the process.¹

A first stage in the development of 'Good Ideas' was the recruitment of four older people, members of the COPA 'hub', as *research associates*. They were given three days training in general research methods prior to the start of the project. They were then invited to opt in to a variety of roles. One person co-facilitated focus groups of carers and also assisted with the analysis of interviews with service users; one associate, who in her work had supported older people with dementia and their families, was co-interviewer; a third research associate, who had worked in senior positions in social care, worked with one of the researchers on the evaluation of the project, on exploring information finding and provided sound advice throughout the project; the fourth associate similarly provided advice, and also represented the team on the Project Advisory Group. Their involvement was invaluable, providing the team with a strong combination of research expertise and life and work experience. An evaluation of the involvement of the research associates in the project is listed in the Appendix.

The *Research Team* therefore constituted staff from RBS COPA, the four research associates, and a researcher seconded from the City of Edinburgh Council Department of Health and Social Care for the duration of the project.

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A *Project Advisory Group* was established of experts in the fields of health promotion, physical activity and older people and nutrition. The 'PAG' provided invaluable support throughout the project, ensuring that advice about nutrition, physically activity etc, as stated in the *Good Ideas* booklet, was accurate and linked to national initiatives. A list of members of the Project Advisory Group is included in the acknowledgements at the front of this report.

3.2 Ethos of the project

In addition to the involvement of older people as researchers, materials were tested initially with one older person who has considerable difficulty in leaving her home. Other older people gave advice and suggestions during the planning of the project.

Consent forms and information leaflets were developed to give potential interviewees as much information as possible to enable them to decide whether or not they wished to be involved in the project. The involvement of 'third parties' – staff from organisations who knew the person being approached – allowed the person to decline the invitation to participate. All those who consented to be interviewed were given a self addressed envelope in case they thought of other issues, following the interview. All were sent a two page summary of the findings of the project.

3.3 Reaching interviewees

In order to gain in-depth understanding of each person's experience of being housebound, it was agreed at the Project Advisory Group that researchers would undertake 'conversational interviews'. The sample size was set at 15 – 18 people over the age of 65, preferably of different ages, gender and living situations. As stated above, the term 'housebound' is interpreted in different ways by organisations and by individuals – sometimes, for example, being applied to anyone who is unable to leave the home without assistance (Ref 11). As the aim of this project was to find ways of better supporting day carers and respite carers who have to provide services within the home setting, it was decided to restrict interviewees to those older people who had great difficulty, for whatever reason, in leaving the home more than twice a month.

The first challenge for the project was in locating older people in this category. This was facilitated by – as recommended in Locher et al (2006) (Ref 12) and Hampton et al (1998) (Ref 13) - relying on the assistance of service providers and others who have close contact with older people who are housebound, who made the initial approaches. At least two people were referred who the interviewers discovered were able to leave their own homes – suggesting that ‘housebound’ does indeed mean different things to different people.

The organisations already involved in the project were unable to provide access to the minimum number of interviewees and a number of other routes were pursued – through both the statutory and the voluntary sectors. For example, Church of Scotland churches were approached, as many provide volunteer visiting services to their parishioners.

The project was carried out by informally interviewing older people and was therefore restricted to older people who were able to voice their opinions. As this was a small study, it was decided not to include interviews with family carers in this study. A further study could include family carers and gather information ‘third hand’, allowing the inclusion of older people whose conditions present the greatest challenge to day / respite carers.

3.4 Those interviewed

Fifteen older people – three men and 12 women - were interviewed. Interviewees were accessed via contacts with voluntary sector staff, a volunteer co-ordinator and Home Care staff from the City of Edinburgh Council. Two were accessed via personal contact and one through contact with a church visiting service. Two other people were interviewed, but not included in the study because it was discovered subsequently that they did not fit the project’s definition of housebound.

Interviewees ranged in age from 61 (a man who is very severely disabled) to a woman of over 100. She did not want her actual age recorded, in case it allowed her to be identified. Three of those interviewed lived with a spouse, one lived with her son who was himself disabled; the remainder lived alone, one with a daughter living close by. Seven lived in upstairs flats, mainly without lifts. Although they could be

relatively mobile within the home, the stairs made it extremely difficult for them to leave the home environment. One lady was housebound by a chronic pulmonary condition which resulted in heavy dependence on access to oxygen.

3.5 Conversational interviews

The research was carried out by means of 'conversational interviews'. This method is less structured than a formal interview, but allows exploration of each individual's daily life, while also gathering information about the areas focused upon by the research. The interviews, which lasted around an hour to an hour and a half, provided a rich picture of the life of each individual.

With the permission of those being interviewed, the interviews were tape recorded and transcribed. The two interviewers and one of the research associates studied the transcriptions to identify common themes, in particular around the areas of nutrition, physical activity and social relationships. These common themes – along with other related topics of importance which emerged as a result of listening to interviewees and to day / respite carers - then formed the basis for the 'prompter' pages in the *Good Ideas* booklet.

3.6 Gathering ideas from day and respite carers

Two focus groups were held at the beginning of the project and one at the end. One day carer preferred to be interviewed. Two day carers who were unable to attend the final focus group were asked for their individual views on the draft booklet and amendments made in response to their suggestions. One difficulty was finding a title for the type of care described in the booklet, as there is no commonly accepted name for a day or respite carer. The research team decided to opt for an inclusive title – *Good Ideas – A practical handbook for supporting older people in their own homes.*

The focus groups generated ideas and information about the activities already carried out by carers – such as one carer facilitating a telephone conversation between an older person who is hard of hearing, and family members; carers attending when physiotherapists or nutritionists visit the older person, to support advice provided; carers routinely spending time with family members at the beginning

or end of the visit, to give them support alongside the support provided to the individual older person.

Good practice examples gathered from the focus groups and interviews highlight the sensitive, creative, approaches used by some carers – approaches which could be encouraged by delivering careful training. The focus groups also demonstrated the value of bringing day and respite carers together, allowing them an opportunity to share issues and ideas between themselves.

The carers particularly appreciated the involvement of one of the research associates in facilitating the interview. As an older person herself, she was recognised as having a particular contribution to make to the discussions.

3.7 Gathering information from other projects

Some ideas for the booklet were gathered by finding out about initiatives elsewhere in the UK for older people who are housebound. Such initiatives could be expanded, adapted or developed elsewhere. Support to housebound older people varies considerably from place to place. The following are a few of those contacted.

Ageing Well (Ref 14) is an established model of supporting health and well being among older people, by recruiting and supporting people over the age of 50 to offer lay health promotion initiatives. Activities are mainly group based, but Good Ideas identified that there may be a role for Ageing Well volunteers in supporting a day carer and an individual housebound older person, as a pair, on a regular basis.

Fit as a Fiddle (Ref 15) is an England-wide programme which is building on the success of Ageing Well, supporting the involvement of older people to promote healthy eating and physical activity.

Walking the Way to Health (Ref 16) promotes walking as a means of returning to or maintaining health.

Upstream (Ref 17) is a healthy living project in Devon which employs community mentors to encourage older people to take part in activities. The project encourages

and supports older people, including those who are housebound, to be involved in group projects. The model has been adopted throughout Devon, by Devon Council (Ref 18).

There are increasing opportunities provided by technology. For example, Hackney Council Community Resource Team (Ref 19) provides individual telephone befriending, but also links isolated older people using telephone conferencing facilities. A voluntary organisation, Community Network, (Ref 20), supports telephone conferencing programmes.

SECTION 4:

Findings

4.1 General

Interviewees were asked about their routines around eating and drinking throughout the day – food preparation, shopping, anything they particularly missed. A picture of the ‘Eatwell plate’, published by the Food Standards Agency (Ref 21) was used to help those interviewed to consider whether they were eating healthily.

Inevitably interviewees relied heavily on frozen food and ready meals, but some continued to manage to cook – for example if someone else prepared ingredients on their behalf. In addition to being able to provide oneself with meal preferences, being able to cook clearly provided a way of passing the day and some satisfaction in being able to continue with a familiar activity.

Some of those interviewed managed simple cooking, sometimes facilitated by equipment such as an electric grill or table top oven. One person who has left her house twice in four years – once for a wedding and once for a funeral – described her love of baking and making soups, which she shared with family members who visited her.

Those interviewed, although spending long periods alone, did not want company at any price. Visitors were appreciated if they had interests, experiences or values in common. The importance of providing the right kind of support – ‘matching’ older person and visitor by age, interests, social background etc., is borne out by Cattan et al (2003) (Ref 22), cited in Cattan et al (2005) (Ref 23)

Company at mealtimes can have an impact on the caloric intake of an older person (Ref 24). Those who lived alone tended to eat alone, although sometimes relatives found ways of sharing meals with them. One person said that having her home carer moving around the house while she was eating provided some company.

One of the Good Ideas prompter pages (p 30) explores some aspects of companionship at mealtimes.

Several of the interviews highlighted the importance of carers supporting older people to continue to do as much as they can independently:

(It's) very important to me ... that I can do these things. I just would feel that I had come to the end of my days if I could not get going"

Miss Campbell, 84, who has dementia, and who likes her home help to leave her with household tasks to do

The daughter of a Chinese older person described how much her mother could still accomplish, if she carried out the tasks that her mother could no longer manage for herself. As stated above, being able to undertake household tasks, however slowly, also clearly helped to pass the time. The booklet points out that these tasks could be shared with a day carer or respite carer. This can assist the older person to remain active and can be a more effective way for a day / respite carer to spend the time with an older person, particularly if the older person has communication difficulties.

4.2 Access to information

At least one older person said at the end of the conversational interview, after looking with the interviewer at the Eatwell plate, that she had not been aware that her diet was unbalanced. She said that she would now make an effort to eat more fresh food. The interviews in general suggested that access to information – such as how to maximise benefits, where to get equipment, how to care for yourself if your life is restricted - may, of itself, assist older people who are housebound to maintain better health and mobility and avoid admission into care or hospital.

"I only discovered last week that there's a gardening scheme in Edinburgh. I didn't know that. I haven't yet discovered how to apply for it."

The research team began to realise that the booklet could have an important role in facilitating access to information. The team were aware that very many voluntary and

statutory organisations provide fact sheets and information packs, often directly accessible from the organisations' web sites. One of the research associates agreed to try to access relevant information about diet and activities. As a member of the public seeking information, she was impressed with the amount of information that is available via the Internet and she found that her requests for information were generally comprehensive and dealt with speedily. However, the difficulty for a day carer or respite carer – or family carer – can be knowing where to start looking. In order to avoid overloading the booklet, it was decided to provide links to key information providers in the booklet, and to encourage day and respite carers, if necessary, to learn to use the Internet.

4.3 Learning from those interviewed

The interviewers were particularly interested in finding out how older people coped with the restrictions of their everyday lives. There were many examples of interviewees adapting to circumstances and to their own particular condition in order to maintain their independence. For example, Mrs Norton (100+) - who continues to live alone with daily visits from a home help - was very aware of the need to stay active, but to be careful to pace herself:

“I fill the kettle at night for the water in the morning for my cup of tea for breakfast and have the trolley ready for my breakfast – all these little jobs keep me on the move, instead of letting everything go and then you have one great big upheaval and you're worn out.”

For someone who is housebound, the home environment can ameliorate or exacerbate their situation. One interviewee, for example, had new double glazed windows. Although reducing heating bills and street noise, she could not open them herself and relied on visitors to open them and close them again as they left.

4.4 The importance of being able to give as well as receive help

The desire to continue to be useful, or involved, or the regret that interviewees were no longer able to contribute to the wider community, was evident from some of the interviews.

“some days I feel quite lonely – in a frustrating way.... I would like to do something from the house, via any mode – the computer or whatever – to give, to the best of my ability – some sort of advice or help...”

Mr Irons, aged 61, who is severely disabled but who enjoyed being a community activist

The booklet suggests ways in which housebound older people could continue to be assisted to be givers as well as receivers - for example, by enabling sharing of knowledge and experience. Supporting involvement in group projects – such as contributing recipes or memories to a book - can have even more beneficial effects (Ref 25).

4.5 The role of day carers and respite carers supporting older people in their own homes

One of the outcomes of the ‘*Good Ideas*’ project may have been to raise awareness about the existence, however limited, of one to one day and respite services. These are particularly important for older people who are housebound and who, as such, are isolated from the wider community, and at risk of experiencing depression and loneliness. Iliffe et al suggest that “*social isolation is associated with higher levels of morbidity and service use*” and that “*interventions that reduce such isolation could reduce the illness burden...*” (Ref 26) If this is the case, there is an argument for increasing outreach day services and home based respite services.

The project has also highlighted the role of carers providing such services, indicating that theirs is a highly skilled task. To be an effective day or respite carer requires the ability to work sensitively and respectfully, acknowledging and responding to the individuality of each older person regardless of their level of frailty or confusion, supporting each person to maintain and make best use of their own resources, and developing trusting relationships with all involved. Carers also need to be able to work in partnership with informal carers – husbands, wives, adult children – to maximise the respite element while also ensuring the older person receives the best possible service during the time the carer has available.

Organisations providing such services need to focus on the provision of person centred support, tailored to the expressed needs and wishes of individual older people and their families. The day and respite carers they support will benefit from opportunities to meet together, and from training in the provision of creative, person centred services.

4.6 Summary

- To be effective, outreach day services and home based respite services need to be person centred and tailored to the needs of older people and their families.
- They need to be provided by carers with whom older people and family carers can form good and trusting relationships.
- Providing this type of care is demanding and requires sensitivity and creativity on the part of carers, and good support on the part of their organisations.
- We can learn from older people who are housebound, and should work in partnership with them and their families to maximise their own resources.
- We can also learn from initiatives elsewhere in the country that promote health and well being.
- Technology could have a bigger part to play in helping older people who are housebound to maintain links with the outside world.
- The types of services described in 'Good Ideas' can help to ensure that older people who are housebound have a reasonable quality of life and that their family carers have others to turn to for support.

4.7 Further work

This was a very small and time limited study. Only older people who were able to take part in an interview were able to express their views directly. Time did not allow the researchers to interview family carers for their perceptions of the role of a day or respite carer. In light of this, there would be additional benefit in further exploring particularly the role of a respite carer – through additional interviews with respite carers, with informal carers, and by observation.

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APPENDIX

Evaluation of research associate involvement – associates' reflections

The involvement of the research associates was monitored over the life of the project. Their experiences and reflections were gathered using the following approaches.

Four times, over alternate months, a questionnaire was sent to associates by post and electronically. A research associate was involved with collecting the information separately from the principal researcher. This was to allow the information to be gathered independently, with the aim of encouraging open and honest comment from the research associates.

At the end of the project, a final questionnaire was administered, again via post and electronically, to capture the associates' journey over the life of the project. This questionnaire was in two parts. Part one used an image format to support reflection. Research associates were encouraged to incorporate other images if they could not relate their experiences and reflections to the set offered. The images were intended to give the associates opportunities to reflect in their own words and not be constrained or guided by questions. Part two comprised of a set of six questions to ensure specific information was captured that may not have been reflected and offered by associates in the image section.

All research associates found the experience of being involved with the project enjoyable from the start – understanding others' points of view, discussing and giving ideas. Geographical location was a barrier for those who lived a distance from the project site and restricted involvement with some activities. All associates enjoyed the experience of working with a new team of people.

(We) felt we were all respected and supported and had a contribution to make

Associates' confidence grew during the project life, leading to involvement in other elements such as analysis of the information from the interviews. At the launch of the booklet an associate volunteered to speak about their involvement with the project. The whole team supported this to happen and is evidence of the growing confidence that involvement can support.

Research Associates used skills from training and built on existing skills from previous experiences. Learning new skills was anticipated as the project progressed. Involvement in analysis is an example of this. There was, however, some uncertainty expressed of how skills might fit with project. Again, distance from project site was felt to act as a barrier and limited the range of activities in which associates could be involved.

Research training to support associates' involvement was piloted for the project. This was enjoyed and found to be relevant and supportive to some in preparation for their involvement, although there was suggestion that this element required further development. The training covered topics of relevance to the research, taking a

general approach. However, a tighter and more direct fit with the project was suggested as a way forward to develop the training for future work.

Other comments from the associates were around training not being sufficiently challenging. Associate feedback emphasised for the team the importance of mapping the group's profile of experience and expertise and exploring their expectations of involvement. Taking this approach highlights the group's strengths: the range of experiences, skills and knowledge held. By understanding these elements, training can be tailored to best meet the associates' needs. This is an important consideration for future training to support involvement.

Some associates reported they found many opportunities for learning about research through their involvement. They developed understanding of the process and procedures - for example, the need to wait for disclosure checks to be processed, the process of interview design, and recruitment. For some, a better understanding was gained of the applications and benefits of research. There was a feeling that patience was needed at times when waiting for involvement to begin. However, once underway the associates commented that the pace of the project increased and was then completed very quickly.

A bit of ups and downs at the beginning. Seemed for a while it was slow to start then the end came really quickly

The background of one of the associates was in research. She welcomed the opportunity to put her expertise into practice without the pressure of responsibility for the whole project.

Associates felt they had been kept well informed about the progress of the project. However, there was a suggestion that a brief project update to accompany the regular questionnaire would be beneficial to all involved.

Benefits to the project

Involvement of the research associates benefited the project in a number of ways. Associates were always mindful of timeframes and targets, and discussions around project activities were always couched in this context. Associates supported the team to keep a realistic perspective on what could be achieved within the scope of the project.

The involvement of the associates as part of the team created a rich collective research group with a wide variety of skills, knowledge and experience. Their experiences ranged from backgrounds in health, social care, construction and justice, with considerable experience of older people's groups, stakeholder groups, management, research experience, and various roles within families to name but a few. This represented a valuable pool of resources that enabled the research team, as a collective group, to gain a variety of perspectives when discussing and considering the progress of the project and the development of the project booklet.

Using a questionnaire method initially proved to be useful, capturing the feelings of the associates at the outset. However, as the project progressed, the associates'

questionnaire returns contained less information. Associates commented that they found very little or nothing new to report from the previous return. This highlights the importance of holding face to face meetings with associates to explore involvement together. Completing questionnaires in isolation may be seen as additional paper work which may not be welcome.

Ideally it would have been the intention of the research team to have used a more participative approach and brought the associates together to discuss their involvement with the project. This would have afforded opportunities to expand on, and further unpick responses with the associates, leading to better understand of their experience of involvement. Unfortunately however, this was beyond the scope of the study at this time.



Project Team



Melanie Lewin, Project Manager



Rena Johnston
Research Associate, COPA HUB



Participants enjoy a Conversation Cafe at the *Good Ideas* Book Launch in March 2009