

A series of research projects about health and social care for older people

**Final report 2013**

# Perspectives on Personal Outcomes of Early Stage Support for People with Dementia and their Carers

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**P•R•O•P**

**PRACTITIONER RESEARCH: OLDER PEOPLE**



centre for research on  
families and relationships



Institute for Research and  
Innovation in Social Services

# An Overview of the Practitioner-Research: Older People Project

## Project overview

The PROP practitioner-research programme is a partnership between the Centre for Research on Families and Relationships (CRFR) at the University of Edinburgh and the Institute for Research and Innovation in Social Services (IRISS). It was funded through the Economic and Social Research Council. This programme also received support from the Scottish Government's Joint Improvement Team.

CRFR and IRISS partnered with a group of Scottish Local Authorities, NHS, third and independent sector organisations to produce this practitioner-research programme. The partners include NHS Lothian, West Lothian Council, Glasgow City Council, Alzheimer Scotland, and Scottish Care and VOCAL Midlothian and Midlothian Council.

This project is underpinned by two key premises. The first recognises that to improve care for older people there is a need for an improved evidence base that relates directly to the needs of those providing services and those developing policy. The second premise is the need to better share this evidence base through greater use of this resource by key audiences and users. One way to achieve both objectives is through the co-production of knowledge between academic researchers and those involved in delivering care.

The PROP project brings together a team of practitioners in health and social care provision, academics and specialists in evidence-use and knowledge media from IRISS and CRFR. Collectively we have synthesized existing evidence, generated new evidence and improved the use of this evidence with the partner organisations. Our aim is to promote a culture of evidence-informed inquiry with the hope that this supports improvements in the lives of older people across Scotland.

## Project Aims

Through the delivery of a practitioner-research programme, we aim to achieve the following:

- Improve the volume and quality of research produced by those delivering health and social care for older people
- Increase awareness of, and improve access to, research created by those involved in providing care for older people
- Support greater engagement and collaboration between researchers and practitioners involved in researching and delivering care for older people across health and social care contexts
- Extend theoretical and practical understandings of the knowledge translation, brokerage and exchange processes that are effective between academics, users, policymakers and practitioners when sharing good practice in the production and utilisation of findings relating to the health and social care of older people

## About Practitioner Research

Practitioners undertake a considerable amount of research, in fact Mitchell and colleagues estimate that 'practitioner research in social work probably occupies a major part of the total volume of research activity in this field' (Mitchell et al, 2010: 8).

There is evidence to suggest that practitioner research can be a valuable approach for strengthening the use of research not just for the individual practitioner undertaking research but potentially for the organisation and perhaps even the sector in which they are based. These benefits vary depending on the support available for the practitioner and how the research endeavour is structured; which can for instance involve support being provided by other practitioners, academics or research colleagues based in-house or in external organisations. Some of the benefits of practitioner research for the practitioner and their organisation can include:

- Delivers research of direct relevance to practice concerns
- Improves research capacity of individual practitioners and organisations

- Strengthens the active role of the practitioner in the research process
- Brings the worlds of policy, practice and research closer together
- Helps an organisation develop the capacity for critical inquiry and a “learning orientation”
- Supports the desire for and the use of research done by “outsiders”
- Reduces the distance knowledge has to travel from research to practice
- Provides a starting point for further research-practice collaboration

(Armstrong and Alsop, 2010; Roper, 2002; Anderson and Jones, 2000: 430)

However, we are not necessarily maximising the impact of research undertaken by practitioners in social services and health for three main reasons:

- 1) Practitioner researchers often lack professional support and training related to the use and application of research methods and theory.
- 2) Practitioners struggle to access existing evidence related to their work, thus potentially affecting the quality of what they are able to produce.
- 3) Practitioners engaged in conducting research into their own team, service or organisation do not usually have the time or capacity to disseminate their research findings or to support its use in other services or organisations.

## **The PROP Practitioner-Research Programme**

This Practitioner-Research Programme (PRP) was delivered between May 2012 and August 2014. Over this period, the nine practitioners involved in the PROP project designed and carried out an empirical research project directly related to their practice and the theme of care for older people.

The partner organisations (Alzheimer Scotland, Glasgow City Council, Midlothian Council, NHS Lothian, West Lothian Council, and VOCAL) made a commitment to support selected members of staff to participate in the PRP. Practitioners were allocated ½ day/week for research, six days for research training and two days for knowledge exchange seminars.

Each practitioner-researcher was allocated a mentor from the University of Edinburgh, NHS Lothian or IRISS. This mentor supported the research design and analysis in the project and provided guidance on how best to use research findings to develop policy and practice.

A series of six training sessions was delivered between July 2012 and February 2013. These full-day events focused on six areas of research practice: (1) resources for research, (2) project management and research planning, (3) research design, (4) generating evidence, (5) analysing evidence, and (6) knowledge exchange.

Knowledge exchange events were held in October 2012 and May 2013 to facilitate learning from these research projects within and across the stakeholder organisations. These events supported practitioners to share and disseminate research findings and provide evidence to partners and stakeholders about best practice.

## **Project Outputs**

The project outputs focus on two areas: (1) improving the care of older people and (2) improving the use and usefulness of research for those involved in providing care. These include:

- 8 completed practitioner-research projects, including final reports and summary postcards
- 1 summary booklet of the PROP programme of practitioner-research
- 2 knowledge exchange events
- 2 peer-reviewed journal articles about improving the use and usefulness of research for those involved in delivering services
- An evaluation briefing paper about the practitioner research project

For more details, please see our website: <http://blogs.iriss.org.uk/prop/>

## **How to Reference this Report**

When making use of this material, use the following reference for this report:

Colston, G. (2013) 'Perspectives on Outcomes of Early Stage Support for People with Dementia and their Carers'. Scotland: CRFR/IRISS.

## **References**

Anderson, G. and Jones, F (2000) Knowledge Generation in Educational Administration From the Inside Out: The Promise and Perils of Site-Based, Administrator Research in Educational Administration Quarterly (Vol. 36, No. 3 (August 2000) 428-464

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## **Contents**

Executive summary .....	1
Introduction .....	1
Background .....	2
Methods .....	2
Ethics .....	4
Findings discussion .....	4
Implications for policy and practice.....	8
Knowledge exchange .....	9
Reflections .....	9
Conclusions .....	9
References .....	11
Appendices.....	12

## Executive summary

This research project seeks to identify the personal outcomes of early stage support provided by Alzheimer Scotland's Dundee Service by conducting semi-structured interviews with individuals living with a diagnosis of dementia who are using the service, as well as their carers and also seeking the views via questionnaire of the staff and volunteers who provide the support.

The narratives were analysed in the context of the Five Pillars of Post Diagnostic Support and the Talking Points Outcomes Approach.

Peer support and community connections were identified by people with dementia as the most important elements of the Five Pillars of the support they receive from the Dundee Early Stage Support Service.

People with dementia, carers and staff were able to identify positive change in the person with dementia as a result of the Early Stage Support Service particularly in relation to confidence.

The semi-structured interviews and staff questionnaire also identified that people with dementia were impacted by the loss of group members.

### Recommendations

- Within the year of post-diagnostic support it is vital that individuals are provided with options for becoming involved with activities that are on-going and enable access to peer support.
- We need to look at managing more effective transitions from early stage support onto more intensive forms of support. This is important not only for the person moving on, but also from the point of view of the group members who remain. The impact of the loss is felt by individuals and the group as a whole.

## Introduction

The decision to develop this research project came about for a number of reasons. There have been three test sites in Scotland evaluating post-diagnostic support but this project was developed via a different funding stream so has not been part of that evaluation. The Early Stage model of support which developed and evolved in Dundee is different model from the test sites that have been evaluated, so being able to describe the model of support as well as look at the various perspectives on the experience of this support- from the point of view of the person living with the diagnosis of dementia, from the family carer and also from the perspective of staff is an important aspect of the project. As a manager I have responsibility for budgets and securing funding for service provision and wanted to firstly raise awareness of this model of support and secondly examine the perspectives of the outcomes for people with dementia of this support as well as carers and the staff and compare them.

As the overall manager of the Dundee Service, my observations appeared to suggest that significant relationships had developed amongst the group members. In addition observations of the Outreach Worker during support and supervision had highlighted to me the learning experience involved in developing this form of support, in particular in relation to the changing needs of the service users and the impact this appeared to have on others in the group. There had been a circumstance where a gentleman made the decision to stop using the Early Stage Support Service as a result of becoming so affected by the loss of friends who had deteriorated more rapidly than him.

This research project sought to identify the personal outcomes of early stage support for people with dementia provided by Alzheimer Scotland's Dundee Service. By conducting semi-structured interviews with individuals living with a diagnosis of dementia who are using the service, as well as their carers and also seeking the views via questionnaire of the staff and volunteers who provide the support.

Personal outcomes have been identified as a way of looking at service delivery from the point of view of the person using the service rather than from the provider. "Outcomes are commonly defined as the impact of activity or support and services...to maximise the person-centred and enabling potential, personal outcomes should primarily be understood as what matters to the person" (Cook and Miller 2012 p8)

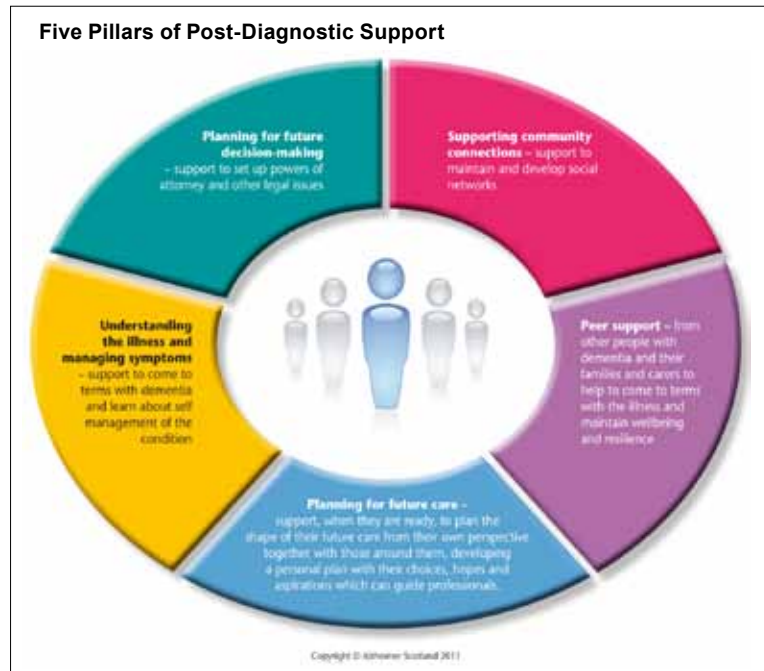
## Background

The Dundee Early Stage Support Service was launched in 2006 as a result of 3 years funding by the Big Lottery and has subsequently been developed and funded as a result of Change Fund Money. The model of support which has been developed is based around developing activities and supports for people who are in the early stages of dementia. This support takes a variety of forms including individual and group activities as well as a Positive Dementia Support Group. Activities over the years have depended on the individual needs and wishes of those using the service and for example have included on-going activities such as- swimming, golf, ice skating, decoupage, gym, Tai Chi, allotment, History Group, Men's Group, Football Memories as well as time limited arts projects including photography, digital stories and dance.

Alzheimer Scotland has described the Five Pillars of Post-Diagnostic Support (Alzheimer Scotland 2011). These Pillars are a useful tool for understanding the different elements that are required to ensure that people who are recently diagnosed with dementia are able to find a way to live well with the diagnosis. Therefore the experiential perspective of individuals who have accessed the Dundee Early Stage Support Service will be analysed within this context.

The Five Pillars have been adopted as part of Scotland's National Dementia Strategy and resulted in the Scottish Government making a commitment to ensure that everyone given a diagnosis of

dementia is entitled to 1 year of post-diagnostic support. This means that for the first time there is a recognition of the importance of post-diagnostic support. This is relevant to this research project as we are exploring the impact and outcomes of an on-going form of support delivered after diagnosis for those in the early stages. The research provides evidence of the experience of having an activities-based form of support in the Early Stages of dementia. This is relevant as there has been a focus on the time limited information based form of support (Gilmor 2012) and this project provided evidence of the outcomes of a different model of support.



## Methods

The overall approach was qualitative in order to gather a sense of the experience of using the early stage support service and what it means to the individuals in the early stage of dementia and their family.

All those who are currently using the service were given the choice if they would like to participate in the research to share their experiences. The Men's Group was approached to let them all know about the research and distribute the questionnaires as well as the Local History and Reminiscence Group. The criteria for inclusion in the research study were that people were currently participating in the Early Stage Support Service, so 22 Research Information Sheets were distributed in total. It was helpful to have the opportunity to distribute the information sheets at the same time as giving a brief talk about the research and it seemed to have an impact on who decided to participate in the research project as four of the five people with dementia were part of that group. I believe that having that face to face interaction to accompany the information sheet helped to reassure them about what it would involve and encouraged them to participate. In total 5 Service Users with dementia and 3 carers were interviewed. Due to time constraints it was not possible for me to follow up on those who did not return the consent

form. I also did not want people to feel obligated to participate either so wanted to ensure they were making an active choice to participate.

Semi-structured interviews were conducted in a place chosen by the person with dementia in order to ensure that they felt comfortable and relaxed and were therefore able to give their optimum participation in the process. Three interviews were held in the person's own home and two were held in the Dementia Resource Centre during a Men's Group session. The interviews took up to one hour each and were recorded and subsequently transcribed. The questions were open ended and verbal prompts were used to enable the interviewee to participate as fully as possible. My role in prompting was to remind the person of key words if they lost the thread when talking to help keep them on track or if the person seemed to find it difficult to understand the question I would rephrase it or use reminders- for example of activities they had been part of. The interviews were kept as informal as possible and my approach was to follow the natural flow of conversation as much as possible. This approach was successful with the majority of participants who were able to respond appropriately in varying degrees to the questions however one person found the process very difficult and became distressed so we agreed to bring the interview to a close.

The language of outcomes is 'service speak'- people do not think or talk about their life in relation to words like outcomes. In order to avoid terminology that would influence the respondents, the questions were open to enable the person with dementia to identify what was important to them about their experience of the service and identify any impact it has had. For example I did not want to ask directly if people felt their confidence had improved, instead I asked what do you feel the impact has been of the service on them. It was important that the words to describe the impact came from the person with dementia themselves.

In relation to the carers, semi-structured interviews were also used. Carers are very busy and could find it difficult to find the time or energy to complete a questionnaire. By arranging to meet at their convenience and recording the semi-structured interview it was hoped that carers would be more willing to participate. As it was 3 carers consented, all of whom were interviewed at home. The timing of the data collection had some impact on the number of participant as it was during December and January and Christmas celebrations put pressure on time.

Within the process of data collection it had not been anticipated that the individuals would wish to be interviewed in front of each other but this was the case on two occasions, where couples chose to be interviewed together.

5 people with dementia were interviewed, all of whom were male and ranged in age from 63 to 76 with an average age of 70. One gentleman had been accessing the service for four years another for 18 months and three for one year. All the men live with their wives. Each person was identified by a pseudonym to protect confidentiality.

To gain the perspective of staff and volunteers a questionnaire via Survey Monkey was used. There are 6 staff and volunteers who have been working closely with the early stage service. The questionnaire asked staff to consider what impact they feel the service has had on people who use the service. The purpose of this research is to identify outcomes for people with dementia and their carers whether they are positive or negative. These questions asked staff to identify what they feel have been the outcomes for individual using the service. This approach was most appropriate in terms of time pressure on professionals and also the relationships the researcher has with staff in the team. The anonymity of the Survey Monkey would be more likely to gather honest views about the outcomes. 3 staff completed the questionnaire- 2 work directly within the service and 1 works with carers and had made a large number of referrals to the service.

To analyse the data firstly, the 5 Pillars of Post-Diagnostic support were (Alzheimer Scotland were used to categorise the narrative response from people with dementia, carers and staff members.

- Peer support
- Community connections
- Understanding the illness
- Planning for the future-decision making
- Planning for the future- future care



The purpose of this was to gain a perspective on what elements of the Five Pillars appeared to be the most important to people living with a diagnosis of dementia as well as carers. Neither the Five Pillars nor the term outcome was used during the interview by the researcher in order to reduce the possibility of the questions leading the person onto an answer. I did not want these terms or categories to narrow the participant' response in anyway. In some ways this made the questions more difficult for the person to respond as they had to find their own words to describe their feelings and opinions rather than have a fixed choice.

Secondly, the narrative was analysed using the Talking Points Personal Outcomes Approach. Categorising responses from people with dementia in relation to the identified outcomes important to service users. (Cook and Miller, JIT 2012)

Outcomes important to service users

Quality of Life	Process	Change
Feeling safe	Listened to	Improved confidence/morale
Having things to do	Having a say	Improved skills
Seeing people	Treated with respect	Improved mobility
Staying as well as you can	Responded to	Reduced symptoms
Living where you want/as you want	Reliability	

**Ethics**

In relation to ethics, all the participants have early stage dementia and have capacity therefore they are able to consent to participate in the research. Consent to conduct the research was sought and agreed by Alzheimer Scotland to approach participants, in accordance with organisational policy and procedures. Gaining consent entailed contacting the Policy and Research Officer within Alzheimer Scotland and completing a Research Access questionnaire giving an outline of the research, who the participants will be, how they will be recruited, what information they will receive and asking to highlight any potential ethical concerns. Data collection and confidentiality was also analysed. Ultimately consent was granted by the Chief Executive of Alzheimer Scotland, Henry Simmons.

In order that participants could decide whether to consent they were each to be provided with an information sheet outlining the research which made clear that it is entirely their choice whether they wish to participate or not. The information sheet clarified that their answers would be anonymous and subject to confidentiality in accordance with Alzheimer Scotland's policy.

In terms of supporting the person with dementia's participation the majority of people who access the service, were known to me through their contact with the Resource Centre. This relationship, as well as an understanding of dementia, helped to ensure that participants could contribute to their full potential. Although this relationship is a positive, it was essential that individuals did not feel obliged to participate or obliged to highlight only the positive aspects. All views and perspectives had to be given, and whether positive or negative would still add to the research. I ensured that this was clear in the information sheet and also when I met with participants. Before I started the questions, I emphasised that the 'not so good things' were as important as the positive feedback as this helped us to improve the service. I specifically asked if the service was worse than anticipated to ensure participants could give negative feedback.

I was mindful that my role as a Practitioner Researcher who has overall management responsibility for the service could influence the responses of participant and I tried to clarify my role as a researcher rather than manager.

**Findings discussion**

**Peer support** was a significant feature of what respondents, both people with dementia and the carers' perspective of the services, found helpful, useful or important about the service. Four of the five people with dementia made reference to it.

*In the group there's different personalities, we get close to each other- plus that's what keeps us going. I'm not frightened anymore... . The ability to mix, didn't happen when I was diagnosed- didn't want to see anyone. Joe 62*

Joe seems to be highlighting the importance of the relationships he has developed as he feels close to the others he has met and also the positive impact of not feeling frightened about living with dementia and feeling able to mix again.

*Get on alright with them, they're good. I get on well with them... gardening and social events. Dancing- that's what I've liked to do all my days. Graeme 76*

Graeme uses the service as a continuation of activities he has enjoyed all his life and having the opportunity to meet with others he gets on well with.

*Meet other people the same as me, the staff help as well. Bryan 72*

Bryan recognises that the other people are the same as him as they have dementia too.

*Out and about meeting different people that was something, rather than sitting here all day. Meeting other people is the best part of it... . Different people you talk to, about different subjects you know. Otherwise it would be a long week looking out the window. George 70*

George appears to feel he would be completely unoccupied without the opportunity to meet other people and for him that is the best part of the service. Both Bryan and George identified the service in being the one way they could alleviate boredom.

All these comments appear to highlight how valuable meeting other people is to these men. Joe identified a difficulty with this however,

*I lost John after 4 weeks (of starting with the men's group). I really liked him and I realised then that I can't get so attached. Joe 62*

Graeme also found coming to terms with changes in other people difficult as he is aware these changes could happen to him also.

*God when I see other folk go downhill. I hope I never get that. Other than that....  
Graeme 76*

This is one area that would benefit from further research. In particular examining the impact of managing the ramifications of witnessing others deteriorating at a different rate to themselves as well as the actual loss of members who move on from the group.

The positive impact of having the opportunity to socialise with peers was identified as important by all the men who participated in the research and it was also a key feature identified by two of the carers

*I remember Wendy telling me about the Men's group. It was music to my ears because Joe's friends he'd lost. He didn't have male company... . I can see how keen he is to go and how much he wants to go. It means the world to him. The Fairmuir Club - he was never a man for the clubbie but he's doing many things with men. Diane, Joe's wife*

*He loves the Fairmuir clubbie has a couple of wee malt whiskies and a chat with the boys... meeting with the guys and girls breaking up the monotony. He needs to socialise and get on these outings. He's getting a break and I'm getting a break... for them to pick him up and bring him back - that's marvellous. Jean, George's wife*

Staff too identified peer support as a key element of the service

*...provides them with the opportunity to meet new people who may be having the same difficulties. This can help counter feelings of isolation.*

*Greatly reduces isolation as gives opportunities to explore different social activities.*

The staff also identified a negative side to the peer support:

*If another service user has a rapid deterioration this can impact on the rest of the group.*

*...another negative part is changes which result in individuals progressing in their dementia stage and requiring further support and support in transition to other appropriate services. Individuals who access the Early Stage Service have discussed actual situations where people have moved on from Early Stage Service into day care and home support services.*

This is an area of practice which deserves further study and consideration of how it is managed from each person's perspective. Support is focussed on managing the transition for the person who is moving on via reviews and conversations about the new plans for support. However there is an identified need to manage the transition from the point of view of those who remain in the group. Joe had also flagged this up during his interview.

All five participants with dementia described the importance of community connections-

*Along came Football Memories – right down my street, always loved football... I realise now Den's Park take care of disabled supporters. Director always says hi – they really care... I had lost my love of football when I was diagnosed; there was nothing in it for me. Football memories encouraged me to go back to football. Joe 63*

Being involved in Football Memories has had a huge impact on Joe he now has a Season Ticket and goes with his wife. This is something that they can enjoy together as a result of re-establishing community connections.

*Dementia Resource Centre - very, very normal, I'm in a situation where I am happy.*

*It (the service) keeps me in touch with the real world. I wouldn't be able to go on without the service. I don't know what would happen to me. It's part of me now, part of my wife. Joe 63*

*Keeps me involved I can't do that at home... I look forward to coming here cos I sometimes get bored. Can't stay occupied at home. Only problem I've got is it get's me down a lot. I worry about it. Bryan 72*

It's interesting that both Joe and Bryan see coming to a specialist Dementia Resource Centre as very normal and helping them to keep in touch with the real world. It has become an important part of their lives and has become a new community connection.

*It's alright going to meet folk and going to Craigie Bowling Club (Service holds regular social events there). Graeme 76*

Graeme uses the Early Stage Service for the Drop-in Café and the allotment and prefers not to be involved with the other groups; however the regular social events we hold in the local bowling club are important to him and keep him connected to a non-dementia specific resource.

*Go to the gym on a Thursday, Men's Group on a Tuesday. Football Memories- been there a couple of times. Fairmuir Club – there's always somewhere to go. Davie he showed us round Dens, I've seen it all... I was interested just to see the old place again... Getting out and about meeting different people and getting transport. If I didn't have transport I couldn't go anywhere. George 70*

*Get out the house... it's important I'm getting no interfere from wife. It's important to me cos I'm a joker. Jim 71*

**Understanding the illness** was mentioned by four of the men,

*Wendy gave me all the books, read them for two weeks, started understanding it... Now that I understand what it is I can accept it. Went into panic mode at first... Scottish Dementia Working Group - great to meet people who are doing well after five years. It's comforting too. Joe 63*

*I didn't know what it was (when I was diagnosed), how it was going to effect me... It upsets me, I speak to God sometimes... you must be doing this for a reason. I won't be any good to anyone. It get's me down a bit. Bryan 72*

*I've grown to accept it now, there's nothing I can do about it so I'm not worrying. There's not a lot they can do even with tablets and drugs. Graeme 76*

*It's important to know what's happening. George 76*

Clearly coming to terms with and understanding dementia is important to these men, however not all of them feel able to be positive about the condition.

In relation to **planning for the future** – whether it was future decision making or planning for future care only one person with dementia discussed this during the interviews –

*My funeral – I know exactly what's going to happen. Big thing knowing I'm leaving my wife with it sorted. Joe 63*

*If things change...natural continuation of my care, more than happy at Morgan Street. I watched them at day care and its brilliant...that's really geed me up knowing that there will be care when I need it. Day care staff make a point of recognising you when you are there. I really want it to be at Morgan Street – the care. Joe 63*

Joe's work before he became ill was within the field of social care for older people. This may be one of the reasons that he has given more consideration to future planning. It did not come up in any of the other interviews when asking open-ended questions.

Analysing the narrative in relation to the Talking Points Outcomes revealed that for the people with dementia using the service all were able to identify ways in which the service had an impact on their quality of life.

*In the group there's different personalities, get close to each other and that's what keeps us going. Joe*

*It's alright going to meet folk and going to Craigie Bowling Club. Graeme*

*Keeps me involved and I can't do that at home. Bryan*

*Getting out and about meeting different people and getting transport. If I didn't have transport I couldn't go anywhere. George*

*It's important I'm getting no interfere from wife. Jim*

Meeting people was recognised and valued by the participants and for Jim it was very important for him to have some space from his wife. Respite is usually considered from the perspective of the carer, however in this instance the person with dementia valued the time away from his wife (carer). This could be a reflection of the changes in their relationship as a result of Jim's diagnosis with dementia causing stress between them.

**Process** was also very relevant:

*Coming into a new situation and finding that staff really respect you... your feelings, your illness. They understand*

*Encouraged to be positive. No-one has ever said poor Joe. Joe*

*I'm alright the way it is I like the company, if the staff wasn't good I wouldn't be long in telling you. Graeme*

*They look after you really well. Bryan*

*All the staff are very helpful, I can ask them anything. All the staff in Morgan Street. In that way it's really helpful to me. George*

People were very keen to praise the support they have had from staff and this may have come through particularly strongly during the interviews as the participants were aware that I am the overall manager of the Dundee Service.

In terms of change as an outcome this was identified by two service users. Bryan said,

*It (the service) makes me feel better*

For Joe the changes were numerous and particularly significant:

*What caused me to start eating again was encouragement of staff plus service users... so nice the way it was dealt with. No-one made a deal out of it.*

*Learned to dance... the confidence I got was unbelievable. I was able to put my stick down week 5. Was always aware of staff around me making sure I was okay.*

*I'm not frightened anymore..*

*I'm now very, very positive. Dementia – I've put that to the side now. I've met so many nice people, I haven't got any worse.*

*Culmination was going to Glasgow on my own (by train)... . Doing the presentation at the (Alzheimer Scotland) AGM gives me a lot of confidence, sometimes I watch it (filmed on his i-phone) and think, 'you did alright that day.'*

Joe has been able to identify a number of ways in which he has experienced change as a result of the support he has had from the Early Stage Service. These changes have had a profound impact on his quality of life and ability to live well with dementia.

Carers also identified change in the person with dementia as a result of the service

*1000% more than I expected, over the past year things he's been involved with, places he's been and the friends. It's taken us from a very dark place to having a future to look forward to.*

*It's the only thing he's keen to do. He's not keen to do anything else... . It's useful because it's making him happy... I want him to be happy I don't want him watching TV all day.*

The carers recognise the positive impact the Early Stage Support Service has had on their husband.

All staff also identified change as an outcome for service users in relation to confidence.

*Increased confidence! I am struggling to think of a single service user who has not felt more confident since accessing the service.*

*A major outcome in which I have seen is definitely a growth in people's confidence.*

*I feel that confidence is something that has had a huge impact throughout my experience in this service. Individuals, families and friends have reported and discussed positive differences and outcomes that the service has given individual people.*

It's significant that positive changes were identified by people with dementia, carers and staff. Dementia is a deteriorating condition therefore having changes and improvements recognised demonstrates the positive impact the service can have.

## **Implications for policy and practice**

Peer support and community connections are the key pillars of support that people with dementia identify as being important. These two elements of the five pillars are the on-going parts which can enable a person living with a diagnosis to manage on a day to day basis.

While it is important that planning for future decision making and future care, as well as understanding the illness, are part of the supports offered to someone post-diagnosis. It is essential that there is opportunity for meaningful activity to be busy and active citizens in society. This has practice implications for the one year post-diagnostic support guarantee. Within this year of support it is vital that individuals are provided with options for becoming involved with activities that are on-going and enable access to peer support.

In terms of the Dundee Service we need to look at managing transition more effectively not only for the person moving onto more intensive forms of support, but also from the point of view of the group members who remain. The impact of the loss is felt by individuals and the group as a whole, and it may be that we need to become better at acknowledging and recognising this loss and change to group dynamic.

## Knowledge exchange

The written report will be distributed to the following individuals/groups:

- Alzheimer Scotland Senior Management Team
- All Alzheimer Scotland staff via the intranet

I will produce a summary of the research and findings to make it accessible to the participants and they will each receive a copy and may also have a copy of the full report if they wish.

In addition I would seek to deliver presentations of the findings to the following:

- Alzheimer Scotland Senior Management Team Meeting
- Alzheimer Scotland Regional Team Meeting
- Dundee Older People's Strategic Planning Group Meeting
- Alzheimer Scotland's Annual Conference or AGM
- Scottish Dementia Working Group

Having the opportunity to present the research will help bring the findings to life and they are likely to have more impact in encouraging people to think about how the findings could apply to their practice.

## Reflections

This whole process has been more difficult and time consuming than originally imagined. It has also been more challenging and exciting than expected. I have worked in the field of dementia care for many years and thought I had a good understanding of communication and dementia. However when conducting the interviews with people with a diagnosis of dementia I was truly in awe of the determination people show to remain able to communicate effectively verbally. It was quite a lesson for me both personally and as a practitioner.

The process of analysis provided the opportunity to listen intensely to verbal communication. Having heard and participated in each interview at the time, then going through the process of listening back to it on multiple occasions to transcribe it gave me a greater understanding of the multiple challenges people with dementia face in terms of verbal communication – understanding the question, understanding the context, trying to stay on track, finding the words, becoming emotional. Repeatedly listening and the seeing the words transcribed had a huge impact on me. Having the time to truly reflect on and analyse the conversations was a learning experience which will inform my practice.

I believe that my experience of being a practitioner assisted me in the interview process as I felt able to be flexible in my approach and respond to the individual needs of service users while conducting the interviews.

There were inevitable tensions in finding the time to undertake the project as a single parent of two young children, working 4 days a week it has been extremely challenging for me to find time to do the work required. Alzheimer Scotland has been very supportive in terms of the scope I had in choosing the research project as well as paying for the extra time I needed to do the research. As a practitioner researcher, practice always had to come first and this led to difficulties in maintaining the momentum. In an ideal world, having a sabbatical to conduct research away from the responsibilities of managing a service would allow the practitioner to immerse in the research process while still coming from a practitioner perspective.

The days at Edinburgh University were very inspiring and it was always reassuring to know that fellow participants were facing similar challenges. This whole experience has been invaluable to me and been very rewarding personally and professionally and I have really appreciated the opportunity.

## Conclusions

This small qualitative study revealed that peer support and community connections are the most important elements of the Five Pillars of Support people with dementia receive from the Dundee Early Stage Support Service.

The study found that people with dementia, carers and staff were able to identify positive change in the person with dementia as a result of the Early Stage Support Service particularly in relation to confidence. This is a significant outcome considering that dementia is a deteriorating condition. Both these findings have an impact on practice in relation to the year of post-diagnostic support. It is vital that individuals are provided with options for becoming involved with activities that are on-going and enable access to peer support as part of this year of support.

Perspectives of the Early Stage Support Service from people with dementia, carers and staff were largely positive however the semi-structured interviews and staff survey also identified that people with dementia were impacted by the loss of group members. Managing transition more effectively needs to be given consideration not only for the person moving onto more intensive forms of support, but also from the point of view of the group members who remain. The impact of the loss is felt by individuals and the group as a whole. This is an area of work which would benefit from further research.

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## Appendices

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19 September 2012

Gabrielle Colston

Dear Gabrielle

### **Application for ethical approval for research from Alzheimer Scotland**

Thank you for your application to access research participants through Alzheimer Scotland's Dundee Services.

We are happy to provide ethical consent to the research study on the basis of, and in accordance with the information provided.

Best wishes with your research study.

Yours sincerely

A handwritten signature in black ink that reads "Henry Simmons". The signature is written in a cursive style with a large, prominent 'H' and 'S'.

Henry Simmons  
Chief Executive

## **Research Information Sheet**

### **Study Title:**

Perspectives on Personal Outcomes of Early Stage Support for People with Dementia and their Carers

Researcher: Gabrielle Colston

Date: October 2012

### **Description of Project:**

This research explores perspectives on the impact of early stage support for people with dementia in Dundee. The study asks the questions

- What are the personal outcomes for people with dementia who use the Early Stage Support Service in Dundee?
- What are the personal outcomes for carers of people with dementia who use the Early Stage Support Service in Dundee?
- What outcomes have staff and volunteers observed in people with dementia and their carers who access this service?

Personal outcomes can be understood "as what matters to the person."

In order to answer these questions both people with dementia who use the service and their carers are invited to be interviewed to gather their views. It is up to each individual to choose whether they wish to participate.

It is hoped that participants would be willing to discuss their experiences of the Early Stage Support Service in Dundee. This project is interested in establishing what the personal outcomes have been as a result of accessing the Early Stage Support Service.

Interviews can be held either in your own home or within the Dementia Resource Centre. The interview will last between 30-60 minutes. With permission, these interviews will be recorded and transcribed for use in the research project. Names of participants will be kept anonymous and confidential. A summary of the interview will be offered to participants for validation. This project complies with the ethics standards set by Alzheimer Scotland.

**Study Title:**

Perspectives on Personal Outcomes of Early Stage Support for People with Dementia and their Carers

Interviewer: Gabrielle Colston

Date:

1. How did you find out about the Early Stage Dementia Support Service?
2. Can you remember how you felt about living with the diagnosis before you accessed the service?
3. What did you think it would offer you?
4. What groups and/or activities have you accessed?
5. How often do you participate?
6. Was the experience of the ESDSS better than you expected, worse than expected or about the same?
7. What aspects of your life has the ESDSS had an impact on?
8. How useful is the service to you?- in what ways
9. How important is the service to you?- in what ways
10. How well does the service consider your individual needs?
11. What do you feel has been the impact of the service on you?
12. How do you feel now about living life with a diagnosis of dementia?
13. Is there anything that we haven't covered that you would like to share with regard to your experiences of the service?

Thank

Reassure

- what will happen to the information
- confidentiality
- results will be made available
- you can contact me with any questions you may have

**Study Title:**

Perspectives on Personal Outcomes of Early Stage Support for People with Dementia and their Carers

Interviewer: Gabrielle Colston

Date:

1. How did you find out about the Early Stage Dementia Support Service?
2. Can you remember how you felt when ... .. was diagnosed with dementia before you accessed the service?
3. What did you think the service would offer ... ..?
4. What do you think the service would offer you?
5. What groups and/or activities have ... .. accessed?
6. How often does ... .. Participate?
7. Has the experience of the ESDSS better than you expected, worse than expected or about the same?
8. What aspects of ... .. life has the ESDSS had an impact on?
9. What aspects of your life has the ESDSS had an impact on?
10. How useful is the service to you?- in what ways
11. How useful is the service to ... ..?- in what ways
12. How important is the service to you?- in what ways
13. How important is the service to ... ..?- in what ways
14. How well does the service consider your individual needs?
15. How do you feel now about living life with ... .. diagnosis of dementia?
16. Is there anything that we haven't covered that you would like to share with regard to your experiences of the service?

Thank

Reassure

- what will happen to the information
- confidentiality
- results will be made available
- you can contact me with any questions you may have