DEVELOPING RESILIENCE IN CARERS OF FAMILY MEMBERS LIVING WITH DEMENTIA

PROJECT FUNDED BY NHS GRAMPIAN CARERS INFORMATION STRATEGY

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There are many individuals whose support has contributed to the following report but the carers themselves are the most important of these. Without the carers the project and therefore the report would not exist. It was not possible to count the number of times that carers asked during their coaching sessions if they were providing enough help! This is therefore the opportunity to record formally my enormous gratitude for their willingness to participate even when they perhaps did not know what was ahead.

Heather Jackson, the Lochhead Day Hospital Manager at the start of the project, helped enormously in the development of the proposal and the early stages of the project. The nursing staff at the Day Hospital along with Julia Wells, Clinical Lead for Mental Health Services, also made the project possible through their interest and enthusiasm.

Coaching sessions took place at the Aberdeen Health Village and at the Recovery Resource Centre at Royal Cornhill Hospital. The logistics of organising rooms was made much easier and enjoyable through the help and support of the staff at both venues.

Coaching supervision is critical to the ability of every coach to maintain and develop their practice. Coaching with carers has particular challenges and Mark Lough who has been my supervisor for a number of years provided tremendous support and insight throughout the project.

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CONTENTS

EXECUTIVE SUMMARY

Introduction

This report is the result of a project funded by the NHS Grampian Carers Information Strategy (NHSG CIS) budget. The potential impact of caring on emotional health and well-being is increasingly recognised in policy documents at both national and local level. Coaching is one method of providing support to carers. This project aims to add to existing evidence developed by the author about the use of coaching.

In summary, the aim of the project was to explore whether or not one to one coaching with carers of family members living with dementia can lead to a measurable improvement in their resilience and ability to cope with the challenges associated with their caring role and responsibilities.

In addition, a comparison took place of carer perceptions of and attitudes towards their caring role and the person they care for before and after the coaching intervention took place.

An assessment of the suitability of a model of a coaching process also took place. This model was developed following the previous NHSG CIS funded project

Method

Sixteen carers participated in the project. The number of coaching sessions attended ranged from 3 to 16. The data on which the discussion and conclusions of the study are based was gained through:

a) two questionnaires delivering quantitative data – the True Resilience Scale questionnaire and the Short Sense of Competence Questionnaire,
b) a comparison of the coaching which took place against the model of coaching developed by the author and
c) qualitative data gathered informally and notes of coaching sessions.

Key findings

All the carers who participated gained some benefit from the coaching. It was shown that one to one coaching for carers can bring a considerable improvement in their sense of wellbeing and their confidence and capacity to manage the demands of being a carer. This study looked specifically at carers in particularly complex situations and led to results similar to those of previous studies involving carers from a wider range of situations and coping with different issues.

The study set out to demonstrate a measurable improvement in resilience. It is acknowledged that the results of the completion of the True Resilience Scale do not demonstrate a measurable improvement in resilience. However, the mapping of the qualitative feedback on to the Health and Safety Executive model of resilience (Appendix 11) demonstrates that the benefits described by carers do indeed equate to an increase in their level of resilience.

This study has also delivered findings in the following important areas

- **Coping with change**
- **Perception of the coach as "expert"**
- **Acceptance and influence**
- **Self-awareness and confidence**
- **Access to services for carers**

The tools used to gather quantitative data did not deliver any data sufficiently robust to draw any meaningful conclusions.

Recommendations

1. There should be a pro-active approach to sharing the findings of this project and to contributing to and developing the existing dialogue about support for carers both locally and nationally.
2. Carers are at particular risk at times of transition so consideration should be given to ensuring there is specific attention paid to offering support at these times.
3. There should be consideration of how to ensure that carers who are currently not engaged with formal carer services can be informed of the support that is available.
4. Formal contact should be made with the relevant Health and Social Care Partnerships through Chief Officers to explore how to develop coaching as a method of support for carers.

CHAPTER 1 INTRODUCTION

It continues to be well recognised that informal and family carers contribute significantly to our ability to cope with a population increasing in age and living with a variety of health problems, often very complex in nature. The numbers of carers and the pressure which this places on them are increasingly visible in both national and local policy. The Scottish Government Equal Partners in Care initiative includes as one of its core principles to ensure that **"carers are supported and empowered to manage their caring role"**. Similarly, the sixth of the nine outcomes required by the recently established Scottish Health and Social Care Partnerships is that "**People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being".**

Previous work with carers undertaken by the author over the period 2010 to 2016 has demonstrated that significant benefits can result from one to one coaching and that these benefits are sustainable. Some of the work was in the form of funded studies while some has been the ongoing delivery of services to carers with informal feedback being provided.

One of the conclusions from the most recent study – "Coaching to equip and empower carers to maintain their emotional health and wellbeing" (June 2016) – indicated that marked improvements in ability to cope and emotional wellbeing were achieved. A further small follow up study took place to assess the sustainability of the initial benefits and confirmed that the benefits remained in place and that for several carers there was continued improvement in their ability to cope and their sense of wellbeing beyond the end of the project.

This report describes a project funded by the NHS Grampian Carers Information Strategy (NHSG CIS) budget. The full application for funding is contained at Appendix 1.

In summary, this project, which commenced in February 2017, aimed to assess the impact of coaching on levels of resilience among a group of carers of family members living with dementia. The carers were recruited to the project via the Lochhead Day Hospital at Royal Cornhill Hospital in Aberdeen. The carers involved in the study were either related to a patient attending Lochhead Day Hospital or were caring for someone attending the Day Hospital. The patients themselves experienced different types of dementia and presented with complex needs which required specialist assessment and treatment.

The project being reported on arose during discussions which were part of the follow up to the 2016 report. Discussion took place with staff at the Lochhead Day Hospital at Royal Cornhill Hospital to explore whether or not it would be useful to study the use of coaching in a specific group of carers, namely those caring for someone with dementia and experiencing complex issues in their day to day situation. The discussion led to a conclusion that while the language of resilience had not been used for the previous project, its outcome indicated improved resilience in the carers in the study. The detailed proposal to explore improving resilience was then developed in collaboration with the Manager at Lochhead Day Hospital

It was decided to undertake a further study with the specific population of carers and to use both quantitative and qualitative measures to assess the impact of the coaching. In particular the project aimed to measure resilience among this group of carers. For the purposes of this study the term resilience is used to mean the capacity to respond to life's inevitable ups and downs and to adapt positively to any situation no matter how serious and stressful it might be.

To date there have been no studies measuring resilience in carers but a well-respected and widely used generic measure of resilience was identified. The True Resilience Scale (Appendix 2) was developed by Gail M Wagnild PhD who has a health care and social care

background. It was felt to be an appropriate tool to use in this context. The use of the True Resilience Scale was piloted with two carers in order to test whether or not a carer would find completion of the questionnaire easy. As a result, agreement was then reached with Gail Wagnild that the measure would be used to provide some baseline and post-coaching data.

The Lochhead Day Hospital Manager was interested to explore whether or not a change in attitudes of carers might be a by-product of the coaching. It was therefore agreed to use an additional questionnaire before and after the coaching intervention to measure attitudes to the cared for person and the caring role. The Short Sense of Competence Questionnaire (SSCQ) based on the Zarit Burden Interview (1983) developed by Steven Zarit (Appendix 3) was used.

CHAPTER 2 PROJECT METHOD

a) Phase 1 – preparation and set up

The main component of the initial phase of the project related to equipping the nursing staff at Lochhead Day Hospital to identify carers who might benefit from coaching and as a result to be able to make an appropriate referral. In order to facilitate the referral process and to avoid bottlenecks as far as possible, it was agreed that all staff would be able to refer carers to the project.

As a result of this, it was necessary to ensure all staff developed an understanding of coaching and what would be involved for any carer who decided to participate in the project. This enabled them to offer coaching to a carer and answer initial questions. Several meetings took place with the staff at Lochhead at the beginning and throughout the project. This accommodated staff turnover and ensured the provision of support and development of confidence which were necessary to identify suitable carers and make a referral.

An information leaflet for carers and a guidance note for staff were made available and these can be seen as Appendix 4 and Appendix 5.

It was agreed that staff could contact the coach by email, phone or text message in order to ensure there were minimal barriers in the referral process.

Nursing staff were informed of the plan to gather both quantitative and qualitative data. In addition, an outline model of the coaching process which had been used for previous studies undertaken by the author was defined. It was agreed that the evaluation process would include an exploration of the extent to which the model reflected the coaching process for this group of carers. (Appendix 6)

i. Quantitative data

With regard to resilience, a tool developed by Gail M Wagnild PhD was identified as potentially suitable, even though it had not been used for carers previously. Gail Wagnild has a background in nursing (including psychiatric nursing) and social work which illustrates the context within which she developed the True Resilience Scale. It was felt that Gail's background and interest in healthy ageing provided a good fit with the aims of the study and that the True Resilience Scale would be an appropriate questionnaire to use in the study.

The True Resilience Scale is normally administered on-line. Two colleagues with experience of working with carers completed the True Resilience Scale on-line and the arrangements which would be necessary for this mode of administration were explored. A decision was made that on-line administration would risk diverting significant time away from the coaching itself. A more suitable paper-based mode of administration was discussed with Gail Wagnild and she kindly agreed to this.

The Scale was tested out with two carers from a previous study. The purpose of this testing was to ensure that the questionnaire was easy to understand and complete. This was confirmed. There was no intention at this stage to explore whether or not the True Resilience Scale would be an appropriate tool for the study.

The Manager at Lochhead Day Hospital was keen to explore the attitudes of carers to their caring role. In particular there was a desire to explore attitudes towards the impact on the carer themselves of the caring role and also to the person being cared for. Work originally undertaken by Stephen Zarit in 1983 had explored carer attitudes. The Zarit Burden Interview (Appendix 7) was developed by Vernooij-Dassen et al and became the "Short Sense of

Competence Questionnaire (SSCQ): measuring the caregiver's sense of competence" (Appendix 3). While the coaching would not be focussing on carer attitudes it was acknowledged that a change in attitudes might possibly be a by-product of the coaching process.

The Short Sense of Competence Questionnaire (SSCQ) was not tested since it had already been used fairly widely with carers.

It was agreed that the questionnaires would be administered at or as soon after the first coaching session as was appropriate. A notional 6 sessions was anticipated. Several possibilities regarding the administration of the post-coaching questionnaires were explored. These included completion of the questionnaires at the final coaching session and then again after 3 months, single completion 3 months after the last coaching session or completion only at the last coaching session. The latter was agreed resulting in two sets of data – one pre-coaching and one post-coaching.

It was agreed that the author would not look at questionnaire results until all coaching session were completed. This was to ensure that coaching would not be influenced by pre-coaching questionnaire results. However, some carers provided some verbal and some written feedback about the True Resilience Scale at the time they completed it.

ii. Qualitative data

Brief notes were made of each coaching session and these included both the content of the session and any feedback or relevant input from the carer. Notes for carers in the form of diagrams and flowcharts were provided. These notes regarding the content of sessions were used to compare the coaching process with the model of coaching which had been proposed.

During the final coaching session carers were asked for feedback. Some provided verbal feedback at the time while others sent written feedback later.

b) Phase 2 – planning for delivery of coaching

Two alternative venues for coaching sessions were identified. One was the Health Village in the centre of Aberdeen and the other was at the Recovery Resource Centre at Royal Cornhill Hospital. It was felt that one or other of these venues would be suitable for most carers and if there was a carer who could not attend either venue then an alternative arrangement would be explored. In the event, all carers were able to attend one or other of the identified venues.

It was agreed that the timing, frequency and number of sessions would be flexible according to carer needs.

The content of sessions would be carer led and would be consistent with the style of coaching described in the author's 2016 study. For detail on coaching approach and style see Appendix 8.

The past experience of the coach was that coaching sessions can often be emotional making the completion of a questionnaire inappropriate. Flexibility about when and how questionnaires would be completed would therefore be necessary. The pre-coaching questionnaire might be completed at session 1 or 2 or taken away and completed at home. The post-coaching questionnaire would be completed at the last session or again taken away and returned.

c) Phase 3 – delivery of coaching

The first carer referral was made in April 2017 and the final referral was in May 2018 with coaching sessions completed by the end of August 2018. The number of sessions delivered

to each carer ranged from 3 to 16, the mode being 6. The detail of this is outlined in Chapter 3.

Consent to participate in the project was obtained from all carers. (Appendix 9) Carers were informed that while no information about the content of sessions would be shared with staff at Lochhead, there would be feedback to nursing staff to inform the referrer that the carer was attending.

Coaching sessions were between 1 and 1.5 hours in length and the content was determined according to the needs and situation of the carer.

d) <u>The coaching process</u>

An in-depth account of the coaching process with carers was included in the author's 2016 study. Little has changed but the account is summarised and updated here.

The coaching process with carers is based on the same principles which underpin every other type of coaching. However, some aspects of the usual principles require particular attention due to the specific characteristics of the context.

The most significant aspect of coaching with carers which differs from other coaching situations is the vulnerability of the client and the risks which arise from that vulnerability. There are risks both to the carer and to the caring relationship. As has been shown through informal feedback to the author during approximately 8 years of working with carers, there are significant benefits to be gained. However, it should be recognised that the very act of pursuing those benefits may bring the risk of damage to the caring relationship.

Many carers have found a way to maintain a degree of equilibrium by avoiding any exploration of how they feel and what they think about their situation. Even though they may have decided to seek help, the reality of the experience of "receiving help" can be hugely challenging and may risk disturbing their equilibrium. A huge amount of trust in the coach may be required and the carer may hold a belief that the coach will protect them from damage during the process. A lack of trust or simply underdeveloped trust may lead the client to reject the process.

A further difference with other types of coaching is the extent to which the coach might share their own views and/or experience. Provided that the intention behind the sharing is legitimate within the coaching context ie it is to support the dialogue not divert it, then it can be very helpful. It might give the carer a sense that their experience is shared by others and therefore does not indicate any deficiency in them or it may provide evidence that the coach does understand their situation which may increase confidence in the coach and the coaching process. It can create the sense that the carer is not alone in their experience and may also help in developing some optimism and sense of the future.

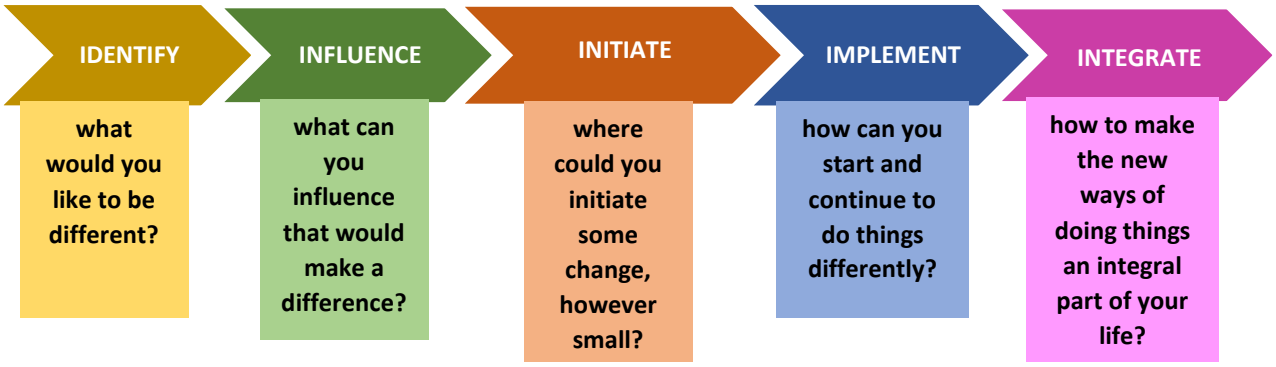
Many of the situations which might arise for carers result in very emotional responses and within coaching sessions there are often emotional situations. As a result, awareness of and acceptance of personal responses to emotions has a prominence that may be less common in a business coaching session.

Finally, because of the strength of the relationship which is experienced by both the coach and the carer, the management of the end of the coaching sessions can present a challenge. The ending of the coaching relationship can be associated with loss. Recognition of this is important. Continued contact after the completion of sessions is always offered. In the opinion of the coach this offer may lessen the impact of the conclusion of sessions and increase sustainability and independence.

e) The coaching model

It was decided to develop a potential model of the coaching process and to reflect on how appropriate it was for carers. The model below was based on previous work with carers and other coaching clients.

Figure 1 Coaching model



At the evaluation stage of the study, the experience of each carer was compared with the model and the conclusions are outlined in Chapter 5.

CHAPTER 3 DEMOGRAPHIC DATA

The number of carers referred into the project was 19. Sixteen carers went on the receive coaching.

One carer did not attend coaching sessions because the person they cared for died shortly after the referral was made and another carer decided not to attend but gave no reason. The third carer who did not attend was enthusiastic but was anxious. They knew that if they were to attend this might lead to very difficult behaviour on the part of the person they cared for. They reached the conclusion that there would be "too big a price to pay" for any benefits.

The group of carers who attended coaching sessions was made up of 12 female and 4 male carers. The age of the carers is shown in Figure 2 below.

Figure 2 Age of carers

Age	31-40	41-50	51-60	61-70	71-80	81-90
Number of carers	1	1	0	7	5	2

The number of coaching sessions attended ranged from 3 to 16. More details are shown in Figure 3 below.

Figure 3 Number of coaching sessions attended

Number of sessions	Number of carers	Comments
3	1	Wife became ill so carer unable to attend
5	1	Carer did not respond to invitations to set up final session after holiday
6	7	
7	2	
8	3	
10	1	The carer's situation was unstable while waiting for the transfer of their relative to a nursing home and then in the early stages of their relative being in a nursing home.
16	1	Carer was awaiting sufficient stability in their relative to allow transfer to nursing home.

Three carers were caring for 2 people. One cared for a husband and son, another cared for a wife and son and the third cared for both their mother and father. The cared for total was therefore 18 made up of 8 females and 10 males.

The group included a father and daughter both caring for the wife/mother. In addition, the daughter was caring for her father. The cared for group was made up of mothers (3), fathers (2), wives (4), husbands (7), sons (2) and one friend.

All carers had a connection with the Lochhead Day hospital either because the person they cared for was a current or recent attendee.

The conditions and ages of the cared for were as shown in Figures 4 and 5.

Figure 4 Condition of the cared-for

Condition	Numbers
Dementia – including vascular dementia and Alzheimer's	**13**
Dementia and Parkinson's disease	**1**
Undiagnosed	**2**
Learning disabilities	**1**
Down's syndrome	**1**

Figure 5 Age of the cared-for

Age	41-50	51-60	61-70	71-80	81-90
Numbers	**2**	**0**	**4**	**7**	**5**

Seven of those being cared for lived in their own home which was not the same residence as the carer, throughout the coaching. Eight were admitted to a care home during the coaching and three were either in hospital or in a care home throughout the coaching.

CHAPTER 4 QUESTIONNAIRE RESULTS

The data collected during this study falls into different categories

1. Quantitative data
    a. True Resilience Scale – questionnaire to measure level of resilience of each carer
    b. Short Sense of Competence Questionnaire (SSCQ) – questionnaire to score the perceptions of each carer of their caring role and attitudes towards the person they were caring for.
2. Qualitative data
    a. Comparison of the actual coaching process with the proposed coaching model
    b. Feedback from carers during and at the end of the coaching process

a) True Resilience Scale data

The pre-coaching completion of the True Resilience Scale took place at the beginning of the coaching process by all 16 carers in the study. However, 3 carers did not complete the questionnaire at the end of their coaching. One carer was ill and did not complete their sessions, a second carer did not complete their sessions because the person they cared for became very ill and the third carer did not complete their sessions for reasons not known to the coach.

The True Resilience Scale measures levels of resilience and categorises them into what are described as Development Stages – Emerging, Developing, Growing and Thriving.

The 13 carers who completed both pre- and post-coaching questionnaires showed the following results.

Figure 6 True Resilience Scale – summary of scores

Carer Number	Pre-coaching stage	Post-coaching stage	Pre-coaching score	Post-coaching score	Stage change	Score change
2	Emerging	Thriving	62	142	+1	+80
3	Developing	Developing	114	116	0	+2
4	Emerging	Emerging	92	102	0	+10
5	Developing	Growing	122	130	+1	+8
6	Developing	Developing	118	122	0	+4
7	Emerging	Developing	111	119	+1	+8
8	Emerging	Emerging	101	102	0	+1
9	Emerging	Emerging	104	96	0	-8
10	Developing	Not completed	122	Not completed		
12	Growing	Growing	128	127	0	-1

Carer Number	Pre-coaching stage	Post-coaching stage	Pre-coaching score	Post-coaching score	Stage change	Score change
13	Growing	Thriving	127	139	+1	+12
14	Growing	Growing	125	125	0	0
15	Developing	Developing	121	114	0	-7
16	Emerging	Not completed	100	Not completed		
17	Developing	Emerging	115	112	-1	-3
20	Emerging	Not completed	83	Not completed		

At the pre-coaching stage thirteen of the 16 carers were in one of the two lower development stages – emerging or developing. Eight remained in one of those stages after the coaching. Eight carers reported an improved score and the score of four carers indicated progress from one stage to the next. Five carers reported a reduced score or no change and eight carers remained at the same stage with one carer reporting no change.

The True Resilience Scale offers a comparison with others who have completed the scale but this is not available for the over 70 age group ie seven of the carers in the study. The remaining 9 carers for whom a comparison is available showed that six were below the average both before and after coaching, two were below before coaching and above after coaching, one was above average before but did not complete the post-coaching questionnaire.

b) Short Sense of Competence Questionnaire (SSCQ) data

All 16 carers in the study completed the SSCQ at the start of the coaching process. The 3 carers who did not complete the True Resilience Scale did not complete the SSCQ either.

The SSCQ measures the following areas

- The impact of caring on personal life eg privacy, ability to meet all demands
- Judgement of self as a care giver eg aspects of the relationship and the strain experienced
- Attitudes to the cared for person eg a belief that they try to manipulate or annoy the carer

A positive change in score indicates a combination of more satisfaction and less negative impact resulting from the caring role.

Figure 7 SSCQ – summary of scores

Carer Number	Baseline score	Post-coaching score	Difference
2	8	24	+16
3	14	19	+5
4	17	29	+12
5	29	31	+2
6	18	17	-1
7	25	26	+1
8	16	19	+3
9	7	17	+10
10	17	Not completed	
12	22	33	+11
13	14	26	+12
14	9	15	+6
15	20	26	+6
16	16	Not completed	
17	25	23	-2
20	18	Not completed	

A positive change in score is evident for 11 carers indicating increased satisfaction with the care giving role and less negative impact. For two carers there was a decrease in score.

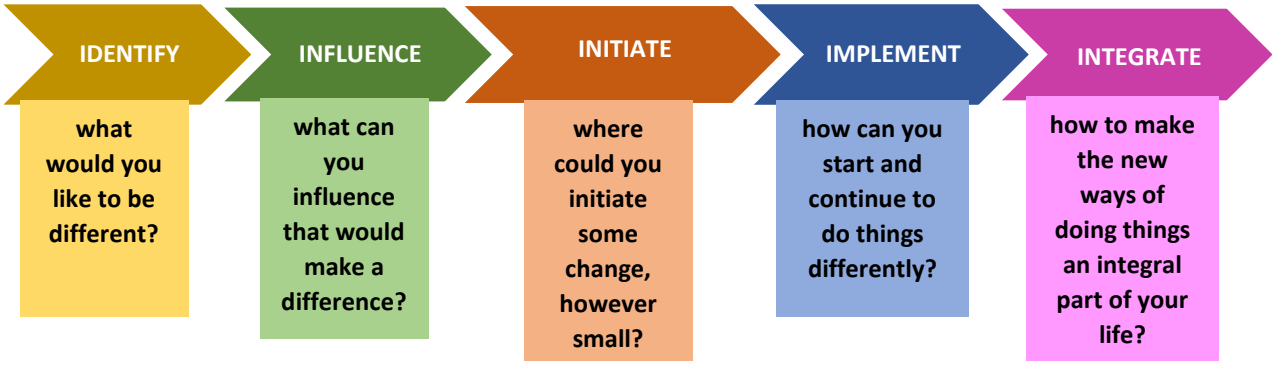
CHAPTER 5 QUALITATIVE DATA

a) Comparison of the actual coaching process with the proposed coaching model

As noted in Chapter 2, a model of the coaching process was developed and it was agreed to compare the actual coaching process with the model. While models can provide a helpful framework, they rarely reflect what actually takes place during coaching. The components of the model may occur at some point during the coaching activity but not necessarily in the sequence anticipated. In addition, other aspects of process are often necessary and can occupy a great deal of the coaching time.

In spite of these reservations, a model based on previous experience of working with carers was outlined. The model was not shared with the carers in the study and no attempt was made to follow the model. It was decided that the comparison would be entirely undertaken as part of the reflective process undertaken by the coach.

Figure 8 Coaching model



Stage 1 – identify what you would like to be different or goal setting

A key component of almost all first sessions with carers was to ask what they would like to be different. Two carers were in an emotional state which was so severe that the question was not appropriate at the first session. In the experience of the coach, this particular question may or may not lead to the ability to set a goal but even without a goal the question provides a good way to initiate the coaching process and it can provide a platform from which to begin.

Of the 16 carers in the study, 7 were unable to articulate what they would like to be different. For two of these, this appeared to be because they expressed little, if any, dissatisfaction with their situation. In both these cases nursing staff had been very concerned about the carer. It had taken some time for nursing staff to persuade these particular carers to participate in the coaching.

One of these carers began with a focus on wanting others around them to change but indeed went on to gain enormous benefits for themselves from the coaching. The other carer was not able to complete the sessions because the person they cared for became very ill.

Five carers were not able to articulate what they would like to be different but were able to describe their situation in a way which easily translated into identifying a goal. Aspects of their situation included

- not being able to sleep
- feeling overwhelmed by emotions
- not doing anything for themselves
- and “everyone has expectations of me which I can’t refuse”.

For these carers it was clear at the start that there was huge acceptance of their situation and the impact it was having on them. This acceptance appeared to be so deep-seated that it was not possible for them either to see that their life could be any different or even to want it to be different.

Even with those carers who were able to identify something they wanted to be different this acceptance of their situation and its impact still featured as a major component of the coaching conversations.

The list below provides some examples of what carers said they “would like to be different”:

- wanting to be less frustrated
- feeling under pressure from the relatives of the person they care for
- help to make themselves more of a priority
- help to “stop me crying”
- help to “bite my tongue” and speak more civilly
- to feel less guilty and less sensitive
- to deal with feedback from colleagues that “I am aggressive and negative at work”

These goals did not dominate the coaching process and content but they made it very easy to commence on something that the carer had a strong desire to change.

Stage 2 – influence or what can you influence that would make a difference?

This stage of the model did not always follow the identification of what the carer would like to be different. However, it surfaced at some point in the process for several carers.

The use of tools to explore the limits of a person’s control and influence were very helpful on several occasions. Four carers had a strong focus on wanting others to behave differently. Family members and/or staff in the facility caring for their relative were the most common. In spite of this, two carers remained very frustrated by their inability to influence others to change.

Hopes and expectations were also explored and one carer shared a saying that had been very helpful to her. It was used with other carers subsequently.

- Accept the changes
- Alter your expectations and plans
- Achieve the best you can.

Development of assertiveness enabled one carer to become very effective at influencing how relatives behaved. Another worked on assertiveness and while it did not significantly change

how others reacted to them it enabled them to feel less frustrated by their behaviour and more accepting of it.

Self-awareness and assertiveness were features of the coaching for 9 of the carers. Significant improvements in the ability to be aware of and to pay attention to their own needs resulted. In addition, there was a change in their ability to accept that this was legitimate and important.

Stage 3 – initiate or where could you initiate some change, however small and

Stage 4 – implement or how can you start and continue to do things differently?

The introduction and continuation of change were constant aspects of the process. Techniques were offered and explored in response to a particular situation. The applicability of these techniques to other situations was then explored. This enabled several carers to develop a generic technique which they could use in a wide range of situations. At subsequent sessions there would be reflection on progress and support and encouragement to continue. The change equation (Appendix 9) proved a useful tool to help with managing and sustaining change.

Exploration of what "gets in the way" of making change and how to practice and develop new "habits" were also part of the process.

Stage 5 – integrate or how to make the new ways of doing things an integral part of your life?

For all carers the final session focussed on how to maintain the benefits gained through the coaching process. The various notes and flow charts/tools/diagrams provided to each carer were a key part of this. Several carers described having a folder of the visual support provided for them and how frequently they referred to their folders.

Nine of the carers experienced the admission of their relative into a nursing home during the coaching process and for two carers their relative was in hospital waiting for their condition to become stable enough for admission to a nursing home. This influenced in a significant way how their coaching process developed. The coaching model was often not apparent or even applicable for these carers. The dominant aspect of the coaching was about simply being, as one of them described it, "with me on my journey".

b) <u>Feedback from carers during and at the end of the coaching process</u>

Each carer was asked for verbal feedback at their final session and some carers also chose to provide written feedback.

Seven carers mentioned a significant benefit was having someone uninvolved to listen to them – someone outside the family, someone who would not judge them. One carer described how "I didn't know what I thought until I heard myself say it". The experience of being listened to was described as encouraging them "to think more about things".

One carer said that the coaching experience enabled them to raise things they hadn't previously thought about and another commented that they felt free to say exactly what they thought. They reported that, in the coaching sessions, "I don't say what I think you want to hear" and that this gave them confidence to speak more honestly in other settings. One

described how good it was to say things that they felt they could not say to their family for fear of being judged.

Coaching sessions rarely included any advice but some carers mentioned that perceptions of the coach as being a professional provided them with confidence in their own views. “Someone I respected listening to me” was valuable according to one carer. The value of the perceived “unconnectedness” and their view that the coach was unbiased provided the opportunity to explore their thinking and to reach conclusions about a way forward which was right for them.

Returning to the value of being listened to, one carer who had been very reluctant to attend the sessions, described how the talking had helped to calm them down and provided relief. It had also resulted in a willingness to talk to others, for example friends and family, who were desperate to provide support. The carer had feared they would be a burden if they said anything other than that they were fine. The ripples that flowed from this change were significant in that this carer talked of speaking to friends more, spending more time with others and seeking their views and support. A second carer said something very similar. This carer had been very reluctant to share their experiences with others but through speaking at the coaching sessions they were now able to speak more to other people. They were also less anxious and sleeping better. This carer mentioned how important it was that Lochhead Day Hospital informed them about the coaching support. Without their encouragement they would not have sought any help.

Another gained confidence from the fact that they felt they were talking to a professional and when the idea was offered that they might consider care for their relative, they started to listen because “you are a professional”.

The increased sense of self as an individual as opposed to as a carer was also prominent in the feedback. One carer said that the time for themselves in the sessions allowed them to feel they got their life back. It also helped to provide a reminder of how they could “be”, implying that this had been forgotten. The “100% focus on me to feel better and stronger” was how another articulated this. “Avenues to explore, encouragement and understanding of my situation” was another quote. “Taking time for myself, being in the present and not worrying so much about the future, as well as not stressing about things I can’t control” was how one carer summed up what they gained from the coaching sessions.

The sessions enabled one carer to raise things they had not previously thought about and they said “I learned about myself and saw things I hadn’t seen myself and others won’t tell you!” One carer who had some major decisions to make regarding the person they cared for said “You put my feet on the path – I might not have done it myself – not believed I was capable or confident enough”.

“Paying more attention to myself and encouraging me to think more about myself” were described by another carer. Similarly, “It’s OK to consider myself and the need to consider implications for my health” indicated that the perceived permission to consider self was important. A significant and unexpected knock-on effect for one carer resulted from changes in their own attitudes which in turn led to their boss listening to them more and asking their views.

Other benefits were described as “helping me to keep things in perspective and perhaps avoid medication”, “helped me not to feel guilty” and “I am now more accepting of myself and I don’t have too high expectations”. Acceptance of themselves and of their limitations was expressed by several carers and for one carer the value of now “feeling OK about how I have handled things” was very important.

One carer who often judged themselves very harshly noted the importance of the reminder that there could be health implications for “my health and wellbeing if I don’t have adequate rest, relaxation and respite”.

“Every time I attended, I felt so uplifted and positive. I fall back a bit but remind myself that I can do it”. This carer made huge changes in that they started taking control rather than leaving things. They stopped taking responsibility for others in the family and they stopped assuming the worst.

CHAPTER 6 DISCUSSION

The use of quantitative data was an attempt to supplement the considerable amount of qualitative data collected in previous studies by the coach. All carers involved in this project were again very willing to participate in the collection of data in whatever way was requested. It was acknowledged that such a small study would be unlikely to yield any robust quantitative data but the possibility of some useful reflection and learning was felt to be worthwhile.

The rationale for choosing to base this study on carers of patients associated with Lochhead Day Hospital included the fact that these carers were coping with particularly complex and challenging situations. Of course, it is difficult to objectively measure the degree of challenge in each carer's situation. However, it was the view of the coach that these carers were indeed coping with very complex and challenging issues. These ranged from the behaviours of the person they were caring for, often aggressive, to their own desire to continue their full-time caring role long beyond what might have been deemed advisable by the professionals. The capacity of the carers was often very low yet their determination remained very high, resulting in significant levels of discomfort and stress.

Several carers were experiencing considerable distress at the start of the coaching process. For some this continued and/or re-appeared at later coaching sessions. As a result, the first session was emotional for some carers and led to a decision to defer completion of the pre-coaching questionnaires.

Coping with change

Coping with a changing situation was a very prominent aspect of many of the coaching sessions. The complexity of the situations experienced by this particular population of carers included

- admission to hospital of the cared for
- searches for a suitable residential facility
- the need to cope with the practical and emotional consequences of moves to care homes.

For some there was a considerable period of waiting for the condition of the person they cared for to become stable enough to make a move from hospital to a nursing home possible. This period of waiting was very difficult and trying to choose a facility that they would be comfortable with often led to considerable stress. Once a move had taken place, entrusting the care of their relative to another agency took time and effort.

In relation to these moves, the focus of coaching sessions included acceptance of the need for change, decision making about the suitability of facilities as well as managing different views within the family. As a consequence of coping with such challenging issues there was a great deal of stress and emotional turmoil for the carers. Development of the ability to be clear about and have confidence in their own views and then to be assertive in situations where their views were being challenged also featured frequently in sessions.

Perception of the coach as "expert"

A dilemma emerged in that some carers perceived the coach as an expert. In spite of trying to be clear that the role of the coach did not include the provision of advice, there was still a credibility attached to ideas put forward by the coach for consideration. The power of this perception of the coach as an expert and a professional appeared to increase the receptiveness to ideas put forward by the coach. This aspect of the coaching was significantly

more prominent than in previous work with carers and may well reflect the significantly more complex situations of this group of carers.

Being aware of the risk that simply helping a carer to open up their thinking may be perceived as offering advice is important for all professionals working with carers. Similarly, there is a major responsibility to take care to avoid the risks of inadvertently influencing the carer.

Acceptance and influence

The acceptance of both the need for care to be provided in a different way and then the acceptance of a new situation presented more challenges. Exploring the limits of influence and control was a part of many sessions in order to help with acceptance. In some instances, the issue was about coming to terms with the fact that we have little or no control over others, for example how children or other relatives of carers behave. In other instances, it was about encouragement to take some control rather than defer to professionals or more dominant family members or friends. The sense of having no control, not only in the past but also the future, was a huge contrast for several carers since in their previous life they had experienced reasonable levels of control and now, in their eyes, they were faced with virtually no control during what was a very difficult transition.

A different aspect of acceptance related to dealing with the behaviour of the person being cared for. Several carers experienced very difficult behaviour from their relative; aggressive, holding the carer responsible for things beyond their control and even quite abusive behaviour are examples. The desire to negotiate and reason with their relative was strong. Encouragement was provided to try a different approach for example of setting a boundary around what was acceptable or walking away were strategies that worked for some carers in that although the behaviour may not have changed, they were able to remain calmer.

Introduction of a model illustrating the circle of influence and circle of control of individuals helped several carers to manage their expectations regarding the impact they might have. It enabled some to shift their focus from what they cannot achieve to what they might be able to achieve. Several were consumed by the behaviour of others – family, friends, care home staff – and began to think about what they could do differently eg become more assertive, to influence the situation. Understanding the limits of anyone's ability to change the behaviour of others was invaluable and helping carers to understand that they could make a choice between acceptance on the one hand and continued stress on the other was useful progress for several carers.

Linked to the subject of control was the sense that the views of others should be deferred to, perhaps because their views were expressed confidently or perhaps because they had previous experience. Such previous experience on occasions served to legitimise their view or was perceived to be more legitimate than what the carer wished for. The coach frequently challenged this view among the carers and one carer in particular made major changes. This particular carer was faced with relatives who were very clear thinking and at times dominant leading to a well-established pattern of deferring to them. This carer gained enormously from becoming aware of their own views and then being able to express their own wishes for themselves and the relative they were caring for.

Self-awareness and confidence

The development of self-awareness to be clear about their own views and then the development of assertiveness to be able to express their views featured in the coaching sessions of several carers. Similarly, the value of self-awareness to allow choices to be made was very important. Carers reported that the choice they made was on occasions the same

choice as the one promoted by others but their feeling of taking some control through making the choice themselves led to benefits.

The pattern of seeking approval for views and decisions, small or large, was broken for some. An associated benefit was the ability to express views and choices in a calm way therefore avoiding the emotional turmoil with family that at least one carer reported. Different types of conversations were reported with more listening to each other and more dialogue.

Awareness of themselves and the development of more positive attitudes to themselves featured in a number of sessions. Carers frequently had unreasonably high expectations of themselves and judged themselves harshly.

Development of resilience

With regard to the use of questionnaires, the quantitative data has been described in Chapter 4 and also how few if any meaningful conclusions can be drawn from it.

The suitability of the True Resilience Scale for carers appears to be in doubt as illustrated by their responses to some of the questions. Key examples of this were the questions where the caring situation resulted in a strongly agree score. For example, “I depend on myself to find a way through anything” and “In a time of trouble, I figure out what needs to be done” were answered with reference to the caring situation and a feeling of no choice other than to find a solution themselves. Similarly, the questions “I have a reason to get up in the morning” and “My life has purpose” were often scored as strongly agree since the reason to get up and the purpose were one and the same – to care for my relative. However, at the same time the qualitative data indicated that a wider purpose in life had been lost to some extent and the reason to get up in the morning related less to this wider purpose and more to a short-term imperative.

Using the term resilience in a less well-defined way, all the carers demonstrated impressive levels of resilience along with the ability to sustain a potentially very unhealthy life for themselves. They were highly motivated with enormous capacity to sustain a life which carried potential risks for them. It cannot be shown by the data that the impact of the coaching was to enable them to avoid those risks but that must be considered. With reference to some of the qualitative data it is clear that some of the benefits that were described could be mapped on to another model of resilience developed by the Health and Safety Executive. (Appendix 10) The qualitative data demonstrates that for several carers self efficacy was enhanced through their increased confidence and associated assertiveness and their reports of being less judgemental and critical of themselves. Some reported a sense of optimism and an increased sense of a future which may be interpreted as part of a personal vision. The acceptance of their situation may be part of some flexibility and adaptability while the ability and willingness to make decisions may be illustrative of a slightly more organised approach to their lives. Problem solving was previously good as shown in the feedback relating to the True Resilience Scale.

Finally, there were reports of talking more to others and allowing others to provide support, as well as embarking on some social activity which demonstrate changes in interpersonal interaction and social connections.

Access to services for carers

The role of the nursing staff at Lochhead Day Hospital was significant in informing carers of the service and encouraging them to receive coaching. One carer pointed this out and the nursing staff themselves spoke of how important this was.

CHAPTER 7 CONCLUSIONS AND RECOMMENDATIONS

As has been shown in previous work by the author, one-to-one coaching for carers can bring a considerable improvement in their sense of wellbeing and their confidence and capacity to manage the demands of being a carer. This study looked specifically at carers in particularly complex situations and led to results similar to those of previous studies where carers were from a wider range of situations.

The tools used to gather quantitative data did not deliver any data sufficiently robust to draw any conclusions.

In spite of this lack of robust quantitative data, the qualitative data from this project reinforces that for some carers one to one coaching should be made available. The task of identifying which carers will benefit most or where coaching should be prioritised remains a challenge. However, investing in the relationships with potential referrers to ensure that they understand coaching and are equipped to have initial conversations with carers undoubtedly helps to target coaching to where it is likely to bring benefits.

This study set out to demonstrate a measurable improvement in resilience. It is acknowledged that the results of the completion of the True Resilience Scale do not demonstrate a measurable improvement in resilience. However, the mapping of the qualitative feedback on to the HSE model of resilience demonstrates that the benefits described by carers do indeed equate to an increase in their level of resilience.

The study has also delivered findings in the following important areas

- **Coping with change**
- **Perception of the coach as "expert"**
- **Acceptance and influence**
- **Self-awareness and confidence**
- **Access to services for carers**

Access to services for carers is an area which must be considered carefully. Even when services are available, carers are not always aware of them and they often need encouragement to avail themselves of the services.

The recommendations resulting from this project are the same as those from previous studies.

One to one coaching for carers is an important component of the support arrangements for carers and a coaching service should be developed. As a very low-cost intervention it represents good value for money.

In particular

1. There should be a pro-active approach to sharing the findings of this project and to contributing to and developing the existing dialogue about support for carers both locally and nationally.
2. Carers are at particular risk at times of transition so consideration should be given to ensuring there is specific attention paid to offering support at these times.
3. There should be consideration of how to ensure that carers who are currently not engaged with formal carer services can be informed of the support that is available.
4. Formal contact should be made with the relevant Health and Social Care Partnerships through Chief Officers to explore how to develop support for carers using coaching.

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