



Person Centred Thinking with Older People

Practicalities and Possibilities



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Care Services Improvement Partnership  

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Foreword

I am delighted to introduce this important new book on person centred thinking and planning with older people.

Older people say they want real choices and the responsibility to choose the best possible lifestyle for them. CSCI's report *Making Choices, Taking Risks* looked at the experiences of older people and carers who need support to live their daily lives. A key message was the need for help to adjust to the life changes (and societal attitudes) associated with ageing - not just to arrange care services. *Practicalities and Possibilities*, and the development programme that will operate alongside it in 2007-08, offers practical guidance as well as a conceptual framework for enabling this to happen so that real improvements are seen and felt by older people in all aspects of their lives.

Older people tell us: *"You spend your whole life making decisions about things - your work, your relationships, your children - you don't want to suddenly give up that responsibility because you're older."*

Government is committed to developing a health and social care system that is founded on personalisation, choice and control. Person centred thinking and planning is a fundamental stepping stone to achieving this goal - and can be applied within and across all public services to reflect the way that older people want to live their lives. It is essential for the way we all think about and work with older people.

For older people this guide also offers some ideas, including practical tools and ways of working with family, friends and services, to ensure they are in control of the support they receive; and aware of the choices they have about the kinds of support that suit them best.

I hope you can use the powerful stories and examples shared in this book, to influence the way you think and act, whether you are a professional, an older person, family member or policy maker.



Dame Denise Platt
Chair, Commission for Social Care Inspection

Introduction

This book is about using person centred thinking to enable older people to have much greater control and say over what they need and want in order to be full and active citizens wherever they live, whoever they live with, and however they live.

Much work has been done - especially over the last 10 years - about developing person centred approaches in health and social care services in order to deliver better treatment and care for older people. However, very often this means doing things in a more efficient and organised way rather than really doing things differently in ways that make sense for older people. Older people also live their lives outside of health and social care services so we need to develop person centred ways of supporting older people that aren't just about quicker, faster, more efficient services, but are about improving lives and life chances. This means ensuring any kind of support is led, designed and planned by and with older people and their families. We also call this 'self directed support'.

Whilst this automatically means that we're talking about a much broader, and more exciting, range of developments and ways of working, it can also seem daunting for professionals who are involved in providing and commissioning services. That is one of the reasons that we wanted to write this book.

Our work at the Older People's Programme and Helen Sanderson Associates brings us into contact with a diverse range of older people, family and other social networks (neighbours, colleagues, friends, wider communities, volunteers) professionals, services and agencies.

Our decision to develop our ideas and experiences into a practical book was influenced by four issues that arose from, or were associated with our work.

The first issue is a reflection on what happens to people's lives if services come to be the dominant part - whether in terms of where someone lives, the arrangement of their daily lives, or the people with whom they have contact. We often meet older people who are living in two worlds - a 'service world' and 'ordinary life'. Most of their contact is with people who are either paid for providing a particular role or who have a formal volunteering relationship. It is often their 'ordinary life' and their ordinary social networks that shrink - and their 'care life' or 'support life' with its 'formal' network that now dominates. Particular problems can arise for older people and their families when the service world starts to dominate and not support - or allow for - an 'ordinary life' to continue or restart.

This 'shrinking' is most likely to happen when someone's situation suddenly and dramatically changes. It can also happen gradually and almost imperceptibly over time. In older age, the most common

reasons for sudden change like this tend to be; illness, disability, bereavement, divorce, or moving to a new place. But the way people have lived their lives in younger years may also be having an impact now. For example, someone may have lived happily with a very small circle or social network of close friends and relatives, but if some of these have now died or are themselves ill there may be fewer and fewer people to call on or do things with.

We are also often struck by how many older people tell us that they have been told to (for example) "come to day care because I was lonely" - but who, when asked, say they are still lonely even though they now regularly attend a day centre or lunch club. Some services, at least, seem to us to be more about a transaction than about transforming someone's life. In other words, there is greater emphasis on delivering something than on making sure that what is delivered is filling the gap(s) identified by the person.

The third issue was initially drawn from a large-scale residential seminar held by the Older People's Programme in 2002 with Help the Aged and Joseph Rowntree Foundation,

which a large number of older people attended. Those taking part in *Living Well in Later Life* (OPP, 2002) identified seven dimensions to achieving a 'good life' - or what is usually known (in health, housing and social care circles) as 'quality of life' or 'well-being'.

The Seven Dimensions are:

- 1 Being active, staying healthy and contributing.
- 2 Continuing to learn.
- 3 Friends and community - being valued and belonging.
- 4 The importance of family and relationships.
- 5 Valuing diversity.
- 6 Approachable local services.
- 7 Having choices, taking risks.

These are placed in roughly the same order of priority or importance identified by those who participated in the event. Whilst this will clearly differ for everyone - all of us have very different things and ideas about what's important in and for our lives - it is interesting to note that all participants placed services and issues of risk right at the bottom of the list!

Key amongst these seven elements is the importance of relationships and networks. But this isn't just about having a list of people you see or speak with - it is very much about the quality and nature of those relationships and contacts, including how time is spent with those other people.

This issue in particular, has struck us time and again; in other words, the central importance of having people in your life with whom you have good, close relationships and with whom you do certain things that are important to you.

Person centred care has been a particularly key focus of developments in health and social care for older people since the introduction of the Department of Health's National Service Framework for Older People in 2001. Standard Two of the framework is: Person Centred Care. Subsequent publications and national guidance have continued to emphasise the importance of being person centred, and developing person centred services and responses to older people's needs. The most recent of these, *A Recipe for Care - Not A Single Ingredient: a clinical case for change* (DH, 2007) is a report from the National



Director of older people's services which reinforces this message about organising and delivering services based on what is important to older people and their families. Within six key factors for improving the way that services respond to the needs of older people¹, the importance of good partnerships with older people and their families is stressed. Working in person centred ways can help develop a different kind of relationship and trust between services and older people so that these partnerships can flourish.

This brings us onto the fourth key issue, drawn from the reactions that we have heard from many professionals and staff working in different agencies and across the public, private and voluntary sectors, which is that they are 'already doing person centred care'. By this they often seem to mean that they are asking older people what they want, or anticipating what they might want, but often without really involving and engaging them as equal and valued citizens (as opposed to service users). We are therefore not always certain about the quality of these conversations; and particularly about whether professional and older people concerned have developed a

sufficient relationship for this to be achieved; and what they then do (if anything) in response to what is shared.

Why is this important now?

Working with older people in enabling and person centred ways has always been important, but there are particular aspects of the current policy and practice environments which mean that this is a high priority to address, and that more people, agencies and influential bodies are ready to listen and learn than ever before.

One of the main reasons is that older people are the majority group of stakeholders in thinking about designing and developing a health and social care system fit for the future – and especially for developments around self directed support, or what some call 'personalisation'. Recent policy frameworks and White Papers, not least *Opportunity Age*, our national strategy on ageing, illustrate the Government's recognition of the challenges and trends associated with our ageing population, including the 'oldest' older people. However, much of the current debate in this policy agenda is concerned with problems in social

care spending and capacity associated with growing numbers of older people who it is assumed will need support in their later years¹.

It does not reflect the varied characteristics of our ageing population, why and how individuals' age differently especially with respect to their health, wellbeing and disability – and therefore their need for different kinds of support. Nor does it tell us much about older people's aspirations, their rights and demands for equality, choice and greater control regardless of their need for support on a day to day basis. Neither does it say much about older people's contributions or about the dynamic nature of ageing – the changing patterns and trends in terms of housing, family and social networks, employment and other types of economic and social participation. It does not recognise, unlike Thomas Perl from Boston University's New England Centenarian Study that the increasing number of older people living to a very old age (such as those living to be 100 or more years) is not a sign of impending doom, but instead:

“These people disprove the perception that the older you get the

sicker you get. Centenarians teach us that the older you get the healthier you have been.”

In all of this it is important to remember what older people want and what they typically experience now if they need support; and especially if they rely on support from services on a daily basis.

What do older people currently experience?

- Fragmented services and support between different agencies, departments, services and teams.
- The health and social care world dominates, and crisis care dominates above all - other parts of your life can often appear to fade away, even though they are central to wellbeing, self esteem and health (e.g. family life and other relationships, being active and contributing, having a role and purpose etc).
- Choice is restricted and support is still largely traditional in nature, especially for older people with high support needs.
- Access to and experience of Direct Payments is increasing, but is still

low overall and in some places is extremely under-developed. Many people are put off at the first hurdle, or leave direct payments if help to unravel or resolve problems is not at hand.

- Whilst it is still early days for authorities and individuals who have an Individual Budget, there are some important early lessons about what helps, what gets in the way, and what matters to older people in taking control of the resources that relate to your support.
- The voices and active engagement of older people are still very quiet, and some older people are very marginalised e.g. older people with mental health difficulties, older people who live in care homes, older people from black and minority ethnic communities.

Person centred thinking and self directed support offer a different approach to thinking not only about services, but also about older people and ageing more widely.

In this book we introduce eight person centred thinking tools, and share older people's stories

and examples of how these tools are used. At the end of each section we suggest where these tools could be used.

We begin this book with a summary of what we are learning about self-directed support and older people, and then introduce each of the person centred thinking tools.

These are:

Appreciations

A key aspect of person centred practice is Appreciation, and having a focus on what we like and admire about people.

Relationships

A relationship map or circle is a good way of identifying and capturing who is important to an older person, to ensure that there is 'at least one person' and to actively seek to widen the connections and relationships that someone has.

What's important to and for people?

The fundamental person centred thinking skill is to be able to separate what is important to someone, from what is important for them.

Important to is about what really matters to the person, from their perspective. Important for is about the help or support that they need to stay healthy, safe and well.

Communication

The communication chart is a powerful and simple way to record how an older person communicates. This is critical if someone doesn't talk, and is also important where people only use a few words, or communicate most powerfully with their behaviours. It can also help if the person has memory or orientation problems, as in the case of people with dementias.

Histories

Older people's histories can easily become lost or be left untold. A conscious effort to listen to and record individual histories can help staff to understand and appreciate people in a different way, and in doing so develop different relationships with them.

Wishing

Older people may be keen to share and explore their own personal goals and dreams - their wishes.

Good days and bad days

One of the ways to discover how best to support someone is to ask about their good days and their bad days.

Working/not working

Simply asking an older person what is working and not working in their life tells us so much. This information may be used to change what can be changed and to help us understand what really matters to people.

We end by exploring how these person centred thinking tools provide the foundation for support planning, and introduce a framework for support planning with older people.

Self directed support and older people

The overarching aims of self directed support are about enabling people who need support to move away from formal mechanisms of delivery where services, agencies and professionals retain control; to a situation where people can live independently and have control over their own lives, and make real choices about the nature and level of support they access from a wide range of networks, options and opportunities.

This chapter summarises some of the early experiences, lessons and observations from the work of in Control members, the individual budget pilot sites, the Circles project working with older people in Oxfordshire and Portsmouth, and person centred planning and support planning with older people in Tameside. It includes information from a background paper prepared for in Control on self directed support and older people and information from an individual budget workshop on support planning.

There is a great willingness to learn more about and apply the practical lessons from developments in self directed support to services and wider systems of support for older people. Some excellent work is taking place in in Control sites and the individual budget pilot sites working with older people to ensure they are taking control over their support needs and the resources to fund them (e.g. with an individual budget or direct payment) so that they can live the lives they want to lead. Whilst there is much to learn from these areas, current progress is limited to relatively small numbers of older people in a few forward thinking authorities and neighbourhoods. There are other innovative projects that are

contributing to our learning, for example the person centred thinking work taking place in Tameside and the Circles Project.

The Circles project run by OPP, worked with over 80 older people and organisations in Oxfordshire and Portsmouth, ran between 2003 and 2005 and explored these issues outside the 'service world' with an emphasis on enhancing quality of life and general wellbeing.

The work was designed to provide practical support, training and advice about establishing and maintaining circles of support for a range of older people, most of whom had support needs of one kind or another. The aim of Circles was to offer a different approach, not only to providing that support (designed and led by the older person) but also to offer the tools and insight into working with older people in a person centred and enabling way, by supporting them to identify and then reach their dreams, hopes and wishes through establishing and/or expanding and strengthening their networks. By working, deliberately, with relatively small numbers of people within these two areas, the Circles project focused in-depth on those individuals' lives and circumstances - both

to better understand what might work and be of value to them personally; and to learn how to adapt 'what works' so that the approach might be shared with larger numbers of older people over time.

By the end of the two year project, this is what older people and others who took part in the work identified as being important in establishing circles of support for them:

- A Circle is the network of people known by an individual older person, however small or large (it may be just one other person), that they identify as being important to them (and to whom they are also important) especially in relation to achieving their personal goals, dreams and ambitions.
- These goals and dreams may be to do with improving health, or recovering from illness or adjusting to a personal loss. But they are also about the fundamental aspects of someone's life that they need some assistance or support to achieve.
- This network or circle includes people with a formal service or support role (paid or volunteer) in the person's life as well as family members,



neighbours and friends. Some people also included their pets as members of their Circle.

- One or more people who the older person knows finding out about his or her wishes, dreams, goals – either by asking directly, or by listening carefully to what is said in general conversation.
- The person(s) who has been told (or has listened) then exploring with the older person whether and how this ‘dream’ or ‘wish’ can be achieved - what would be needed and who might help. This includes exploring the true extent of the older person’s network and supporting them to develop and maintain this network or circle when needed.
- The person(s) providing this support in turn seeking their own support – for example to find out different ideas or contacts that might be useful from within their own networks including colleagues.

Our focus in the stories that are shared from the Circles project in this book, is on extending and strengthening older people’s personal networks, to enable those circles to work together with the older person to achieve their dreams, goals,

hopes and/or aspirations that each has identified would make a difference to their lives and overall well being. These are stories of how people’s lives and/or circumstances changed over a fairly short timeframe (12-18 months in one case, but much less for most other people) through the practice of circles of support and applying the principles of ‘person centred [life] planning’.

At its simplest, Circles was a project about how some older people were asked what they would like to do, have or be – and how they set out to achieve these ‘dreams’ without extra money, specialist staff or new services, or by having every aspect of those dreams ‘done for them’ by someone else.

We believe there are important lessons to learn and use from all these approaches; but there is also a lack of awareness about what is possible and achievable. For example, at present there is far greater understanding about self directed support within those areas that are pilots for testing out and trying new ways of working and developing services (e.g. the Individual Budget pilots, the POPP pilots, Link Age Plus pilots, Innovation Forum pilots and so on).

There is now a need to share, and a desire to learn, these important lessons with authorities that until now have had little input regarding self directed support and person centred thinking with older people. At the same time, we want to make sure that these lessons and approaches are adopted across all public services in relation to older people, rather than being seen as a priority for health and social care alone.

We hope this book contributes to sharing information about how person centred thinking can be used to enable older people to direct their own support.

What have we learnt so far?

A consistent theme across different pieces of work and experiences of using person centred thinking and planning with older people is the importance of starting with, and reinforcing, the fundamental concepts and principles of self directed support and individual budgets. The key points are summarised here.

- Self direction is about choice and control over any assistance and support you need to live your daily life.

- It is about people's lives and improving their quality of life and sense of control - it is not about health and social care or service based solutions, even if for some people these are crucial for day to day survival.
- Introducing the approach, concept and seven step framework of self directed support with personal experiences and lives (i.e. stories) is enormously helpful - for staff as well as for individual older people and their families and friends.
- There is a pattern from working with people with a learning disability which probably means that the person concerned is already known to you, and that everyone involved is familiar with the concept of starting with lives not needs. In addition, person centred thinking and planning with people with a learning disability is often about working with someone who has never been in control before, or had very little control over their lives. With older people the work is often about rebuilding or renewing control for people who have lost control due to ill health, exclusion, discrimination, life events etc. It is important to recognise different starting

points and histories – which will vary from person to person.

- The fact that there are many more older people than there are people with a learning disability - combined with the transient and intermittent nature of many older people's involvement and contact with services - may explain the relative newness of self directed approaches in this field.
- Whatever the reasons (and there are many!) - it's important to start emphasising the potential, the different contexts, the benefits and opportunities for individuals and the system generally - through stories, life histories and biographies of people's lives. Starting with, and reinforcing throughout, the impact on personal experiences and lives will help shift cultural, societal and professional expectations regarding older people (and ageing) away from illness, dependence and frailty towards independence, control, contributions, aspirations and fulfilment.

We have found that the core seven step process for self-directed support developed by

in Control, and person centred planning tools and techniques such as those developed by Helen Sanderson Associates and the Learning Community for Person Centred Practices, seem to work well with and for older people. However, we need to extend this and learn in more detail the specific circumstances where these might need to be adapted. We also need to learn more about the implications both for starting to work in this way with older people, and in ensuring that the ethos and practice of self-directed support continues as, or if, individuals' needs and circumstances change.

An important finding from talking with different places who are exploring these issues is that support planning, a key stage of the seven step process, is a meaningful way for older people to understand self directed support themselves, and for families and staff (and others involved in supporting older people) to begin working in this way. We explore this later, as this builds from the person centred thinking tools that we will begin to introduce in the next chapter.

The following box, Summary of Early Lessons, further highlights these points.

Summary of Early Lessons about Self Directed Support and Older People

The 7-Step (in Control) Framework is a helpful and practical tool that can be used to test “readiness” and review progress as well as a framework for implementing self directed support

Self Directed Support is NOT just about money

- The biggest attraction for older people is increasing control and having a different menu of support.
- Support Planning is therefore crucial.
- Personal stories are really important. We therefore need to get better at using older people’s experiences, knowledge, skills, talents and aspirations.
- This is still a new concept for many people and organisations.
- There is a lot of good practice in dementia care that is not widely shared.

The starting point for older people is usually different from disabled people

- Older people have often experienced ‘cumulative loss’ and lost control (rather than never having had it).
- Funding streams, eligibility criteria and ceilings are different (usually lower).
- The first contact older people have with services, and how their need for support arises affects everything (e.g. in a crisis).

There is an uneasy fit between self directed support and current systems of care

- There is much to do to bring about a closer fit which involves transforming local systems across all public services. It's important to start small and learn about what helps to become person centred at all levels.
- Work on simplifying assessment systems (e.g. through the Single Assessment Process, or the Common Assessment Framework) needs to learn from this fundamentally different approach. Person centred thinking and planning is not a bolt on efficiency saving device. It is a different philosophy and approach which has implications and benefits for how services organise themselves to deliver support differently.
- Both specific and broader 'policy and practice hooks' should be used to influence change at a local level:
 - Opportunity Age - our national strategy on ageing.
 - Sure Start to Later Life - combating social exclusion of older people.
 - The work of older people themselves e.g. through Older People's Advisory Groups, Older People's Forums and Councils (e.g. Brighton and Hove Older People's Council, Newcastle's Elders' Council).
 - Partnerships and Older People Programme (POPP) pilots.
 - Strong and Prosperous Communities, the Local Government White Paper (DCLG, 2006).
 - Forthcoming Housing Strategy for an Ageing Population.
 - Transformational Government for Older People work led by the Cabinet Office and the Pensions Service.

Person Centred Thinking Tool 1

Appreciations

Although in many cultures older people are honoured and revered for their wisdom and experience, in western society – including the UK - this is often not the case. The famous poem, ‘Crabbit Old Woman’ reflects the way older people may be seen in hospital, and certainly how older people themselves feel themselves to be seen.

A key aspect of person centred practice is Appreciation, and having a focus on what we like and admire about people. This is counter-cultural, and therefore focused attention is required to remind us how important it is, and the difference it can make.

What we appreciate about someone is crucial for developing and building a relationship with someone, so for staff it is a critical but often overlooked first step in getting to know someone and playing a part in the most intimate aspects of their life.

Appreciation can also help families and friends to re-discover their relationships with an older relative or neighbour, so is therefore important for maintaining and renewing the ties we all have with different people in our lives. This can be particularly helpful if someone has developed a dementia and has lost aspects of their memory or association with other people in their lives.

Appreciation then, is fundamental to person centred thinking and person centred support.



Asking ourselves what we appreciate about somebody can be a really good way of starting to work in this way - to taking a step back and seeing who that person is, and appreciating their qualities and strengths. This helps to counter our tendency to focus on how much support an older person needs.

Mary Groves

Mary says she has had a great life. She is 91 and has lived at Oakwood House for the past two years. She says;

"I have a lot of living to do yet. I'm not going anywhere until I'm at least 200!"

She is happy and content, and likely to burst into song when you least expect it. Every Saturday, her sister and niece, Susan and Agnes, visit. Mary loves these visits. Staff asked Susan and Agnes to consider

what they appreciate about Mary. Not many people are asked these questions about their relatives, and they were surprised and delighted to contribute.

This is what they came up with:

What we appreciate about Mary

- A fantastic, cheeky sense of humour.
- An eternal optimist.
- Affectionate and loyal.
- Very nurturing.
- Sociable and caring.
- Infectious giggle.
- Very kind.
- Honest.
- Laughs so easily.
- The warmest person I know; you instantly care about her.
- Positive attitude and so funny.
- Always lifts my spirits.



- Feel better for talking with her.
- A smashing character.

Mary glows as this list is read to her. She uses it to introduce herself to new members of staff, and says that it makes her 'feel loved and valued.'

Florrie Ward

Florrie is 98 and has lived for 21 years in Tree House, a residential care home just outside Manchester. (*Gill Bailey explains how she got to know and worked with Florrie and the staff at Tree House*). When we first met, I noticed how isolated she appeared. The staff at the care home rarely talked to her. When I asked staff to tell me a little about Florrie, they did not seem to know who she was as an individual. She was another mouth to feed, someone else to clean and dress. The fact that she sat quietly in the lounge gave staff time to attend to other people.

After spending time with Florrie and getting to know her I discovered a gem of a woman, full of wonderful stories and humour. She captivated me with her tales about her life in service from 1920 to 1970.

Cooking and baking have given Florrie great joy over the years. She loved nothing more than to cook slap up meals and bake delicious cakes for the household where she worked. She will tell you she was 'married to her job' but had to give it up when 'her legs gave up on her'.

I began to gather information about what mattered to Florrie and how she wanted staff to support her. I worked with the staff team on this, and we wrote the information on one page (a one page profile). This helped staff see Florrie differently. Six months later, to develop the information further, I asked the team what they liked and admired about Florrie. Florrie

What we like and admire about Florrie

Her wonderful outlook on life!
Her ever present smile & the joy she brings.
Her total honesty & integrity.
Her stories
She is so charming
Her charisma & beautiful nature
I just love her.



Florrie's gifts

Her wonderful recipes that cook follows to make wonderful Victoria sandwich cake, Lemon Meringue pie & numerous others.
The squares she knits to make lovely warm blankets to keep us warm in the winter and for our grandchildren

Florrie

does not have any family, so the list reflects solely staff perceptions. We wrote this on a separate page, with a photo of Florrie, and it hangs in her bedroom. I was amazed at how the responses differed from those of six months ago. As a result of knowing what is important to her and how best to support her, staff now truly see Florrie for who she is.

One staff member said,

"I was really upset that after working at Tree Lodge for 9 years, I didn't even know that Florrie had led such an interesting life or worked as a housekeeper. We never get chance to talk because we would get in trouble if the chores don't get done".

How can this tool be useful?

First contact with a service

As outlined by these stories, the Appreciation tool and one page profiles can make a huge difference to both older people and their families, and to staff in getting to know someone and understand who they are – rather than just seeing an older person as a set of needs or problems to be sorted out. It can help to build trust and

confidence in the service for the older person and their family. It sends a very strong message that this person is important, that staff care about you, and that knowing you matters to us.

Moving to a new place

It is not just with services and staff that getting to know someone and their unique personality and story is important. Many older people move on retirement, if they are bereaved or if they suddenly become unwell or disabled. All of these circumstances may of course bring them into contact with services of some kind; but will often bring them into contact with new people in their lives - some of whom will have a specific role or purpose, which may be short term. If an older person is moving to a new kind of domestic arrangement - for example to supported or warden assisted housing or a care home, Appreciation and one page profiles can be a practical and insightful way of finding out what's important about and to an older person as the first step in building new relationships and friendships.

Assessment

At the beginning of any assessment for identifying support or other needs (and

therefore what services might help), one page profiles give a more complete picture of who someone is. In addition, this person centred thinking tool is an important aspect of assessment itself and can be built into the first or contact assessment (of the Single Assessment Process), and added to as additional information, reviews, etc are built up over time.

Planning support and care arrangements

Following assessment, because of the richer, personal information that this tool elicits, what follows in terms of support plans and care arrangements are more likely to be of direct relevance to the older person, shaped by their own version of events, circumstances, and their personal situation. It is really important to think through, with the older person and others in their network (or circle) how to translate the information from a one page profile into the kind of support that really makes a difference to that person's life, health and wellbeing.

Reviews

As part of a review, a one page profile will help the person and staff/others working with them, to focus on what is positive

as well as anything that may be difficult. Asking staff what they like and appreciate about someone helps to identify who has a personal connection to someone and who knows what is important to them.

Day to day activities

One page profiles used in tandem with the other tools in this book should also reflect the wider picture of someone's life, not just what they need to help them do certain tasks. It is important therefore to make sure that Appreciation and one page profiles are not used in isolation from these wider aspects of the person's life, but instead deliberately set out to capture and record them.

Families, friends and neighbours

This is where friends, neighbours and family members have an important part to play, especially if the person has memory or orientation problems or a particular way of communicating that needs to be explained and understood. Involving family and friends in building this personal portrait of someone, alongside the older person, is a good way of establishing positive relationships with that person's network.

Person Centred Thinking Tool 2

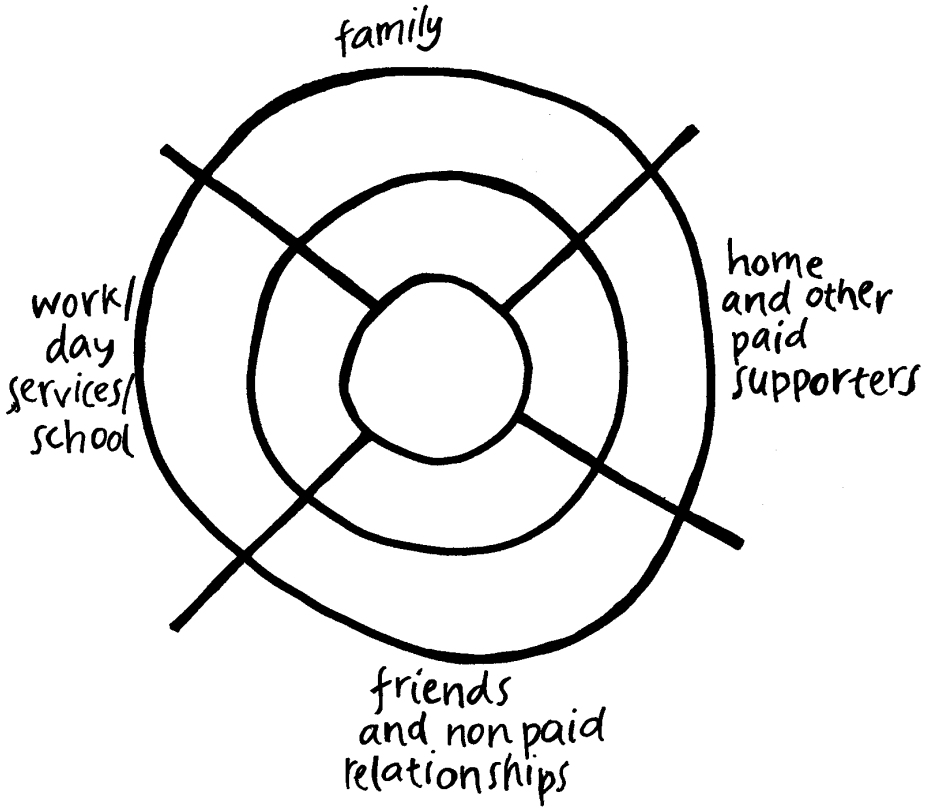
Relationships

Relationships are everything. As Paul Tournier says,

"It is impossible to over-emphasise the immense need people have to be really listened to, to be taken seriously, to be understood. No one can develop freely in this world and find a full life, without feeling understood by at least one person."

A relationship map or circle is a good way of identifying and capturing who is important to an older person, to ensure that there is 'at least one person' and to actively seek to widen the connections and relationships that someone has. It can also identify the nature of those relationships i.e. how someone knows the people in their life, and in particular the one person or people who are important to them.

This can be represented in many ways; one commonly used approach was developed by Judith Snow and uses circles. The following is an adapted version.



Jakob Kravits

Jakob is 78 and lives in a council flat in Portsmouth, but is originally from the Ukraine. He was a refugee in Germany before moving to the UK in the 1970s. English is his third language. His marriage to an English woman broke down many years ago, and it seems their child had died.

When we² first met Jakob he didn't know anyone in Portsmouth, and had no living relatives. Although he was not eligible for any social care service, he had been ringing the duty social work number several times a week, in great distress.

Jakob was very reluctant to leave his flat and was generally very anxious and unhappy. He talked about going to Leicester where he lived with his ex-wife - even though he did not know anyone who lived there. When social workers had visited him (following his calls) he had not wanted to pursue anything

that they suggested in the way of local support, such as the social services funded shopping service (to help him think about taking care of himself and eating well), the local Good Neighbours scheme (a volunteer run befriending scheme). Other than ringing the duty social work number, Jakob's only other contact was with his Tenancy Support worker. Using an adapted relationship circle helped Jakob to discover that he really wanted to meet people and make friends. He was lonely, isolated and very unhappy.

Jakob's Tenancy Support Worker, Julie, helped him to think about his relationships.

She was already involved in his life as she was helping him sort out some rent arrears and benefits claims. Julie was able to expand and adapt her job to include person centred approaches like Circles of Support. Jakob seemed very comfortable with this, because



“This approach helped me to get further and faster with Jakob once the initial crisis (in this case, problems with finances) was sorted out.”

he had already begun to build a relationship with her. They had conversations about what he wanted in his life and how he might achieve that.

Jakob’s life changed a lot over the next few months. He significantly expanded the number of people in his relationship circle. Equally importantly, where he was extremely reluctant beforehand to try anything, he began to try all sorts of things of his own volition.

Soon Jakob:

- Was going regularly to a new, monthly Age Concern ‘Gentleman’s Club’, getting there on his own, on public transport.
- Was playing chess with a man he met there who shares his love of the game.
- Had visited the local D-Day museum with his new friend.
- Had attended a local voluntary organisation’s Christmas lunch,

where he met more people who he wants to see again.

- Had offered to teach another man chess in return for computer lessons.
- Goes to his local pub occasionally on his own, for a quiet drink,
- Has asked to go on the waiting list for a Good Neighbours volunteer to visit him.

Julie also quickly no longer needed to see him as his Tenancy Support worker, because that role and its associated tasks was fulfilled. She had adapted her day-to-day work to include the Circles approach. Her involvement with Jakob did not continue for longer than it would have done in any case.

Jakob no longer calls the duty social work team and no longer seems worried about or interested in revisiting Leicester.



Audrey Peters

Audrey, 73, had been widowed for 18 months when we first got to know her. Her daughter, who lived some distance away, was very worried that her mum had 'lost' her previous outgoing personality and sociability. Audrey and her husband had not long moved to Portsmouth (from South Wales) when he died.

At the beginning, she told us that some days she would get on any of the buses that stopped at the end of her road, and just stay on it in the hope that she would find someone to have a chat with that day.

Audrey worked with a Circles facilitator for five hours of visits. They began by developing Audrey's relationship circle. They had a focus for each visit or meeting that they held. Audrey particularly enjoyed being set a small task to report back on at the next meeting. Over five visits, these tasks

included: completing the mapping of her own circle; going to a local computer club for which her facilitator had found details; going to the local Methodist church and collecting a copy of their newsletter and details of services.

This approach seemed to help Audrey by enabling her to take several small steps that led cumulatively to large changes in her life. It also helped her facilitator to plan each visit, to start the conversation each time, and to make sure progress on Audrey's goals and wishes was kept on track.

By the end of these sessions Audrey told us she had:

- Joined a club.
- Made five new friends (including a potential friendship with her 'facilitator').
- Gone out twice to the theatre with some of these new friends.

- Found and employed a regular gardener.
- Enjoyed a new craft session at the club and continued with it at home.
- Become much closer to her daughters, brother and sister-in-law.
- Made plans for a trip to the USA to see her Canadian based daughter.
- Had plans to find a Methodist church to worship at again.
- Had plans to learn to use a computer.
- Had plans to become a 'Good Neighbours' volunteer.

By the time her facilitator finished these five sessions their friendship and regard for each other was growing. They hoped to stay in contact even when the work relationship was over, and had already enjoyed a theatre trip together.

Audrey's circle has grown significantly. She has now added the following people to her relationship circle:

- Three friends at the Monday Club.
- A friendship with the local Mr KleenEzey.
- The gardener.

- Her facilitator.

Audrey also importantly identified that some of her existing (not close) relationships had changed. She had felt able to tell her brother and sister-in-law and her two daughters something from her past that she had kept secret for a long time. She also shared this secret with her facilitator, but did not want it shared with anyone else. She was willing to tell us, through her facilitator, that she felt much closer to those people as a result.

Audrey felt that the changes in her life were all down to the facilitator; but the facilitator was equally clear that nothing would have changed had Audrey not been willing to try and to do as much as she had. Audrey was very pleased when this positive message was shared with her, as she felt they should now both be shining our halos.

How can this tool be useful?

Completing a relationship map can help to:

- Identify all the people in your own and someone else's life - and the range of different relationships you have with them.

- Explore and understand the balance between family, friends and staff in someone's life. In particular relationship circles or maps can pinpoint when and where someone has moved from a situation of having had many people in their life, to maybe having one or two or only staff in their life - and the impact this may have had on that person.
- Improve or increase staff awareness - and family members - about who is in someone's life, who used to be in someone's life, the kinds of relationships that person has had before, and may or would like now.
- Discover relationships that could be developed - for example if someone has moved to live in a new area, or in supported (or sheltered) housing, or a care home - and they don't know anyone else there.
- This in turn can help to increase an older person's participation in community and family life.
- Understanding the network of relationships that an older person has (however small) can help family and friends to continue to be involved in that person's life, by ensuring that those providing support (especially on a formal or intensive basis) are aware of and facilitate these relationships to thrive. This is especially important if circumstances change and the person's need for support increases or they move to supported accommodation.
- Give a much fuller picture of someone's life, which in turn can inform a support plan.
- Is an important first step in getting to know who is in an older person's life and what role they play, and could play in providing support and/or enabling them to have a good quality of life.



Person Centred Thinking Tool 3

What is important to and for people?

The fundamental person centred thinking skill is to be able to separate what is important to someone, from what is important for them. Important to is about what really matters to the person, from their perspective. Important for is about the help or support that they need to stay healthy, safe and well.

In using this tool people need to be able to separate what is important to and what is important for the older person, and to find a balance between the two.

Services are usually very good at describing and delivering what is important for someone - for example what medication the person needs, how they must be positioned, how to make sure they are clean. If the older person needs a lot of support, especially on a daily basis, their nurse or carer may record this. Alternatively, it may just be passed from carer to carer. What is usually missing in exchanges like this, is what matters to the person, how they want their support provided, and the balance between the two.

Arthur Jones

Arthur is a charming man, a real gent. People describe him as the salt of the earth, a real character. He is 86 years old and lives in his own flat in Moss Side, Manchester. This area has featured on the national news due to the number of drug related shootings, which is an issue for Arthur's family and carers, as, if he becomes confused, he tends to go outside in the middle of the night.

Arthur is terrified of being put in a home. His family and carers are doing their best to help him stay in his own home. He has support from home care workers four times a day to prepare his meals for him.

Stephen and Sally (Arthur's nephew and wife) talked with Arthur and his carers and recorded what they know is important to and for him. They captured this on one page to share with everyone who

supports Arthur. In this way, they hoped that his care workers could get to know Arthur and what matters to him, and therefore be able to provide support in a way that really worked for Arthur.

What is important to Arthur

They thought that it was important that the care workers know that Arthur sometimes likes to talk about his time driving tanks in the war, but only when he is in the mood. He also likes to talk about the old boxers especially Cassius Clay but he doesn't relate to the name Muhammad Ali. Arthur loves talking to people and is an amazing storyteller. He has lived in his flat for 35 years. His wife, Madge, died 20 years ago and he treasures her wedding ring, which he wears on his little finger.

What is important for Arthur

Arthur has very poor vision and hearing, and his walking stick

"They used to leave a butty in the fridge for lunch. I hate butties. Anyway, I get a nice bit of soup or a hot pot now, something warm you know. You can't beat it. It's tons better now. They sit and have a cuppa while I eat my meals – it's miserable eating on your own, day in, day out you know." Arthur Jones

must always be to hand as he has quite an unsteady gait. He finds his way around his flat quite easily but should never go out alone.

Arthur's carers have a key to get in his flat. If he is in bed, they must never approach him, as he would think it was a burglar and hit out with his walking stick. They find calling his name from the bedroom door works best. Arthur always wears his wool bob hat and will tell you he is sick and tired of people telling him to take it off - he will say, 'This is my flat and if I want to wear my hat I'll wear it'.

Arthur makes sense of his days by sticking to his routines. Anything out of the ordinary will totally disorientate him, leaving him confused and likely to go outdoors in search of help. He always has a £10 note in his top pocket 'in case he needs it'. If he loses it he will struggle on his hands and knees for hours looking for it. If

something out of the ordinary is happening - such as a hospital appointment - carers need to explain this clearly to him about a week beforehand and remind him daily. Arthur goes through phases of believing he is really ill and you are keeping it from him. Carers need to reassure him; joking that it's old age catching up with him will make him have a good old laugh with you.

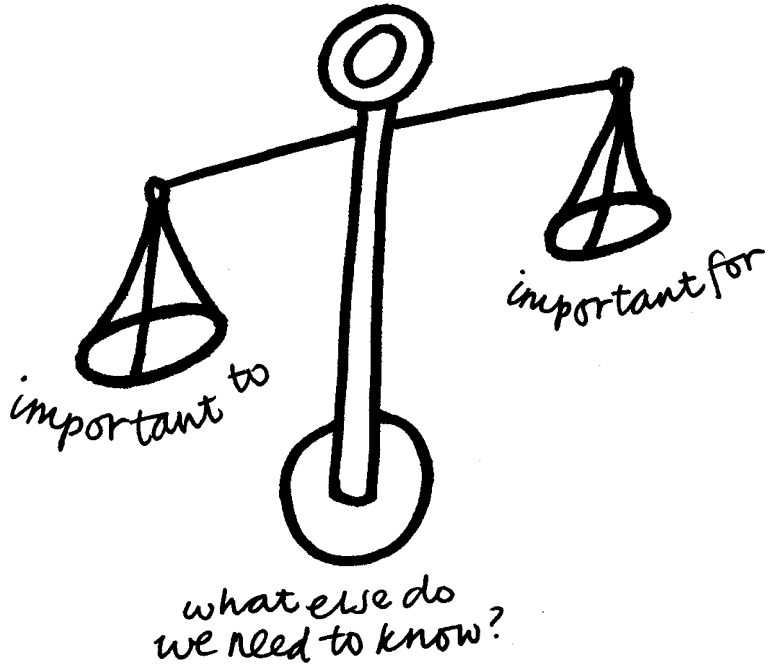
Balancing what is important to with what is important for Arthur

What is important to Arthur is to have hot meals and not to eat alone. What is important for him is that he does not go out alone, and has his food brought to him.

Arthur's carers were bringing sandwiches and leaving them in the fridge for him. Arthur hated this, and would throw the sandwiches into his back yard, which encouraged rats,

and created a pest problem for Arthur and the local residents. The balance between important to and important for here was for the carers to bring Arthur hot food, and to stay and chat while he ate this.

Arthur pays for this himself, and it costs an additional £37 per week. Well worth it, from Arthur's point of view, as he now gets hot meals and someone to talk to at lunchtime everyday.



What is important to Arthur

Always have his walking stick within reach.

That people sit and talk with him, and listen to him too – he loves company and is an amazing storyteller.

That people sit with him when they call to serve his breakfast, dinner and tea – he dislikes eating alone. He loves his meals to be piping hot.

Seeing Sally and Stephen every other day.

That you listen to his stories, especially about the war, but never instigate a conversation around the war – he only talks about it when he is in the mood.

That you can talk about all the old boxers with him – Cassius Clay is favourite but he will not refer to him as Muhammed Ali.

Knowing if anything is happening that is different from the normal routine.

Must always have at least £10 in his pocket.

Must wear his wool bob hat when he wants and not be encouraged to take it off – he likes wearing it and becomes agitated when people suggest he takes it off in the flat.



How best to support Arthur

Arthur worries that he is very ill and people are keeping it from him – give him lots of reassurance that it is just old age – he will have a good laugh with you then.

Always explain very clearly to him about any upcoming appointments usually at the hospital – do not tell him at the last minute.

Arthur has very little vision and is hard of hearing, when you enter his flat via the keypad code you will need to call out to Arthur that you are there, if Arthur is in bed never approach him, he will think you are a burglar and will hit out with his walking stick.

Arthur is frightened of being 'put in a home' – tell him that we are all doing our best to help him stay at home, but when he goes outside in the middle of the night we are frightened he will get hurt.

What those who know Arthur say they like and admire about him

Charming.

Salt of the earth.

A real character.

Full of humour.

A real gent.

Just the most gorgeous gentle man.

Arthur



Nora Hughes

You can also use person centred thinking skills for specific areas of people's lives.

Nora lives in Oakwood House, a residential home with seventeen other people.

Nora is 87 years of age, and is a real character, full of chuckles and fun. She has a beautiful dress sense. She loves to see her sons and daughters Tony, Jim, Margaret and Irene.

The managers of Oakwood house wanted to continue to improve the service that they offer people. They thought that one thing that they could change that would improve the quality of everyone's life, would be to look at the evening routine at the home. They worked with all the staff at the home to give them an understanding of and confidence in person centred thinking skills. The staff worked with a person centred planning

co-ordinator and developed, with each individual in the home, a description of what was important to each person about their night time routine, and what support each person needed (what was important for them). The managers then worked at making sure that what was important to each individual was happening so that people were getting support in the way that they wanted it.

What is important to Nora

Nora needs her routines to run like clockwork, everything has to happen at a certain time, otherwise this will develop into a bad evening and night for Nora.

It is really important to Nora that other people living at Oakwood House do not go into her bedroom, although she is happy for staff to enter her bedroom. Nora must begin getting ready for bed at 7.30pm. As soon as the music comes on at the end of Emmerdale, Nora's favourite



soap opera, she will take her feet off her footstool, remove the rug from her knee and look in an obvious way at the clock.

Nora washes her face herself using Dove soap, she loves to wear clean clothes each night for bed and must choose which nightie to wear. Nora also chooses the clothes she will wear the following day whilst getting ready for bed. Nora must have a body wash each evening in order to feel comfortable and clean for bed, she has talc on after her wash, no particular favourite but usually scented. Nora loves her four pillows to be arranged comfortably once in bed, she is only comfy with lightweight covers and must have cotton sheets and a bedspread. She must not have a duvet! Nora loves her small lamp by the bed to stay on all night and the bedroom door to remain open.

What is important for Nora

Staff should acknowledge Nora's wishes around other people living at Oakwood House not going into her bedroom and support her with this respectfully, by speaking to the other people living there when necessary.

Nora's reliance on routine are central to her happiness and staff need to be aware of Nora's cues when she is ready to go to bed and respond - this will invariably be at 7.30pm. Two staff should support Nora from her armchair into her wheelchair to go to get ready for bed in her room. Nora needs support to use the commode in her room, she will then have a wash. Nora needs support in filling the sink with warm water, Nora's flannel then needs to be soaped up with her Dove soap so as she can wash her face, the cloth then needs to be rinsed and handed back to Nora so as she can rinse her face, she will then dry her

face herself. Nora chooses from 3 nightdresses, which staff hold up, Nora will fix her eyes and say yes to the one she wishes to wear for bed. Nora always has clean underwear and pad for bed. Two staff should support Nora into bed and then arrange her 4 pillows comfortably around her. Nora's bedroom should always be warm enough for her to sleep comfortably, with just a cotton sheet and bedspread, if it is very cold Nora may like a blanket. Nora's small lamp must be left on and her door open.

Balancing what is important to, with what is important for Nora

It is important to Nora that when she goes to bed, she can look through the long mirror on her wardrobe. She could then see whether there were people in the corridor. This helped Nora feel safe and secure. Nora would become upset and anxious when the night staff shut the door. The door was a fire door and regulations dictated that it had to be closed. Nora would sometimes struggle to get out of bed to open the door again, only for night staff to close it again as they did their round.

Although what was important for Nora was being met, as she

was safer from fire by having a fire door, this was not in balance with what is important to her. It is important to her to look through the mirror out into the corridor.

Steve and Sheila had a magnetic smoke detector fitted to the bottom of the door. This means that Nora is still safe from fire (important for her) and has what is important to her, as the door stays open and she can look through the mirror into the corridor. This cost £200, but means that Nora can now sleep through the night, rather than being anxious that somebody may be out on the corridor, her door can remain open which means she can go to sleep relaxed in the knowledge that if she wakes in the night she can look through her long mirror out onto the corridor.

How can this tool be useful?

Assessments

Knowing what is important to and important for an older person can be instrumental in enabling an accurate and sensitive assessment to be carried out of someone's personal needs and circumstances. Balancing the important to, with important

Important to Nora about going to bed

As soon as the music at the end of Emmerdale comes on Nora likes to go to bed. Nora will take her feet off her footstool, remove the rug from her knee and look in an obvious way at the clock.

Nora washes her face herself, she uses her Dove soap.

Nora loves to wear clean clothes each night for bed, she chooses which nightie she will wear.

Nora must choose the clothes she will wear each evening for the following day.

Nora has talc on after her wash, she has no particular favourite, but usually uses the talcs she has received in gift sets over the year.

Once in bed Nora must have her four pillows arranging comfortably.

Nora must not use a duvet, she prefers cotton sheets and a bedspread – she is only comfortable with lightweight covers.

That her small lamp by the bed stays on all night.

To support Nora in her evening routine

At 7:30pm two staff need to support Nora from her armchair into her wheelchair to go to get ready for bed in her bedroom.

Support Nora to use the commode in her room.

Fill the sink with warm water and soap Nora's flannel up with her Dove soap so that she can wash her face. Rinse the flannel for Nora to rinse her face. Nora then dries her face herself.

Nora always has a body wash which she needs staff to carry out for her.

Nora doesn't use any creams unless prescribed by the doctor but she likes a fine layer of talc sprinkled over her body before putting her nightie on.

Hold three clean nighties up for Nora to choose the one she would like to wear.

Nora always has clean underwear and pad for bed.

Two staff need to support Nora into bed. Nora has four pillows as she sleeps in an upright position.

Nora's bedroom should always be warm enough for her to sleep comfortably with just a cotton sheet and a bedspread – if it is bitterly cold out ask if she would like a blanket.

Ensure Nora's small lamp is left on.

Nora's evening routine

for (where assessments tend to be pitched) can help to keep an assessment focused on the person, their story, their view of their needs and what will help to meet them. Person centred assessments are a key part of national policy as well as person centred practices for individuals. Finding out about and recording what is important to and important for someone helps to keep assessments truly person focused.

Planning support and care arrangements

Having a record of what is important to and important for someone makes the process of translating the outcomes of an assessment into clear and personalised support plans and for organising other care arrangements much easier. It can also be a good way of checking back with the person that what is recorded and what is set out in a plan makes sense to them, and matches their understanding of what has been agreed or identified in a plan.

Reviews

Taking stock of what is important to and for someone, can help in reviews, to check that their support is working well for them, and to identify where things can be improved.

It can also help to pinpoint important changes in someone's situations or support needs.

Dementia care mapping

There are many synergies with these person centred tools and approaches and the practice of dementia care mapping (DCM), which was developed by the late Professor Tom Kitwood and Kathleen Bredin in the later 1980s. It is designed to assess the quality of care experienced and delivered to people with dementia from the perspective of the person with dementia. It is used most often in formal care settings such as hospitals, care homes and day centres. It is based on the philosophy of person centred care, promoting an holistic approach to care that upholds the personhood of the person with dementia. Knowing what is important to, and what is important for someone, is a fundamental concept within dementia care mapping. Even without the more specialist aspects of DCM, knowing what is important to and for someone with dementia is a crucial part of getting to know that person and how to best support them to live the life they want to lead. More information about dementia care mapping can be found on the website of the Bradford Dementia Group www.bradford.ac.uk/health/dementia/dcm

Person Centred Thinking Tool 4

Communication

Having the power to communicate and to be understood is central to older people being able to have choice and control in their life - in fact, to have any quality of life at all. It is easy to assume that older people who cannot talk have little to say. Nora, who we met in the previous chapter, can only say 'yes', yet has at least four different ways of saying it, each conveying a different meaning. She has plenty to communicate, if we can also listen to the subtleties of her expression and body language.

When many staff support someone, each staff member may have a different idea of what the person is communicating with their behaviours or words.

The communication chart is a powerful and simple way to record how an older person communicates. This is critical to someone who doesn't talk, and is also important where people only use a few words, or communicate most powerfully with their behaviours.

The communication chart has four headings:

What is happening describes the circumstances.

What the person does clearly describes what the person says or does in enough detail that someone reading the chart who has not seen this behaviour would still recognise it. Where it is something hard to describe, (e.g. a facial expression), you could

use a picture. Some people have even developed video communication charts.

- **We think it means** describes the meaning that people think is present – a best guess. It is not uncommon for there to be more than one meaning for a single behaviour. Where this is the case, all of the meanings should be listed.
- **We should** describes what staff should do to respond to what the person is saying with their behaviour. This section gives us an insight into how the older person is perceived and supported.

It's easiest to complete a communication chart by starting with the two inside columns (starting with When does, and then moving onto We think it means). Following this, work out to the two outside columns (What is happening, and We should).

As an example, Nora's communication chart is on the following pages.

How can this tool be useful?

Thinking about communication patterns and techniques is fundamental to person centred

support and ensuring that older people are able to participate as full and active citizens no matter where they live or their support needs. The four level model described above is a practical and helpful way of breaking this issue down into manageable chunks. It makes it much simpler for everyone to understand.

Thinking differently about what is happening to a person (or around them), looking at and interpreting what the person is doing or communicating using non verbal signs and cues, and exploring what this means in order to support someone well - are all helpful in the following situations:

First contact with a service, new staff, volunteer or group

For example:

- In hospital, especially if admitted in an emergency or crisis.
- Being discharged home from hospital, to be supported at home often by a different team of people.
- Attending outpatient appointments, or a new kind of service or support group (e.g. employing a personal assistant, going to a mobility

What is happening/ where/when	When Nora does this	We think it means	And we should
<p>Anytime.</p> <p>Nora is being asked to make a choice or answer a question, for example choosing her clothes.</p>	<p>Nora shouts 'yes'.</p> <p>Nora says 'yes' but her facial expression is cross and her tone is sharp.</p> <p>Nora smiles and says 'yes' enthusiastically.</p>	<p>She wants to go to the bathroom.</p> <p>No, she doesn't like the item of clothing you are showing her or the answer to the question is no.</p> <p>Nora is telling us 'yes'.</p>	<p>Support her to the bathroom.</p> <p>Respect the answer to the question is no.</p> <p>Show her more options when choosing her clothes.</p>
<p>Nora is being asked to make a choice or answer a question.</p> <p>In the evening.</p>	<p>Nora will take her feet off her footstool, remove the rug from her knee and look in an obvious way at the clock.</p> <p>Nora grimaces and says 'yes' in a cross tone or swears.</p>	<p>She wants to get up out of her armchair and go to bed – usually 7.30ish.</p> <p>She is unhappy – perhaps her routine has not run like clockwork, the nurse is late or early (Nora hasn't finished her breakfast), somebody may have gone in her bedroom or she doesn't like what is on TV.</p>	<p>Depends on the question or choice but respond accordingly, letting Nora know we understand she has told us 'yes'.</p> <p>Check with Nora if she wants to go to bed. If so support her (see Noras' going to bed routine).</p> <p>Sit and talk to her.</p>
<p>Anytime.</p>	<p>Nora holds your hand / smiles at everybody.</p>	<p>She is happy.</p>	<p>Enjoy her company.</p>

Nora's communication chart

What is happening/ where/when	When Nora does this	We think it means	And we should
<p>If Nora has swore at you at some point that day/night.</p> <p>Anytime</p> <p>Anytime</p> <p>Anytime</p>	<p>Nora takes your hand and says 'yes, yes, yes' in a positive way.</p> <p>Nora shouts and shakes her finger.</p> <p>Nora tilts her head to the side and utters words softly.</p> <p>Nora is very quiet and does not smile.</p>	<p>I am sorry, forgive me.</p> <p>Nora is angry or frustrated.</p> <p>Nora is feeling sympathetic towards somebody.</p> <p>She is feeling sad or bad.</p>	<p>Reassure her.</p> <p>Talk to Nora. Acknowledge her anger/frustration.</p> <p>Acknowledge her kindness.</p> <p>Talk to her – ask what is wrong.</p>



Nora's communication chart

or independent living centre for the first time, attending a day centre or drop in/lunch club for the first time, and so on).

- Moving to a new place or area.

Assessment and care plans

If someone does not use many words to communicate, it is vital that any assessment or care plan builds this into an assessment, and that any support or care plan includes a communication chart.

Reviews

If someone has a communication chart, then a review is a good opportunity to look at this. Check that it is up to date, that everyone is using it and that it is working well for the older person.

we want to tell...	to do this we	helped/ supported by

at this time	when this happens	we think it means	and we do this



Person Centred Thinking Tool 5

Histories

Our histories make us what we are. Older people's histories can easily become lost or be left untold. A conscious effort to listen to and record individual histories can help staff to understand and appreciate people in a different way, and in doing so develop different relationships with them. This can also happen within families - especially between different generations. There are many ways to capture and record histories - for example with photographs, family trees, scrapbooks, through miniature histories in objects, with graphics or simply by writing them. Websites and commercially available packages can help to capture family histories, and most families would be delighted to help.

Cliff Richard's mother has dementia and lives in a residential nursing home. He had a glamorous photo of her, taken in the 60s, hung above her bed. He wanted staff to see who she had been in her life, not just how she seemed now. A powerful photo or graphic can speak a thousand words.

HISTORY OF HILDA

KEY



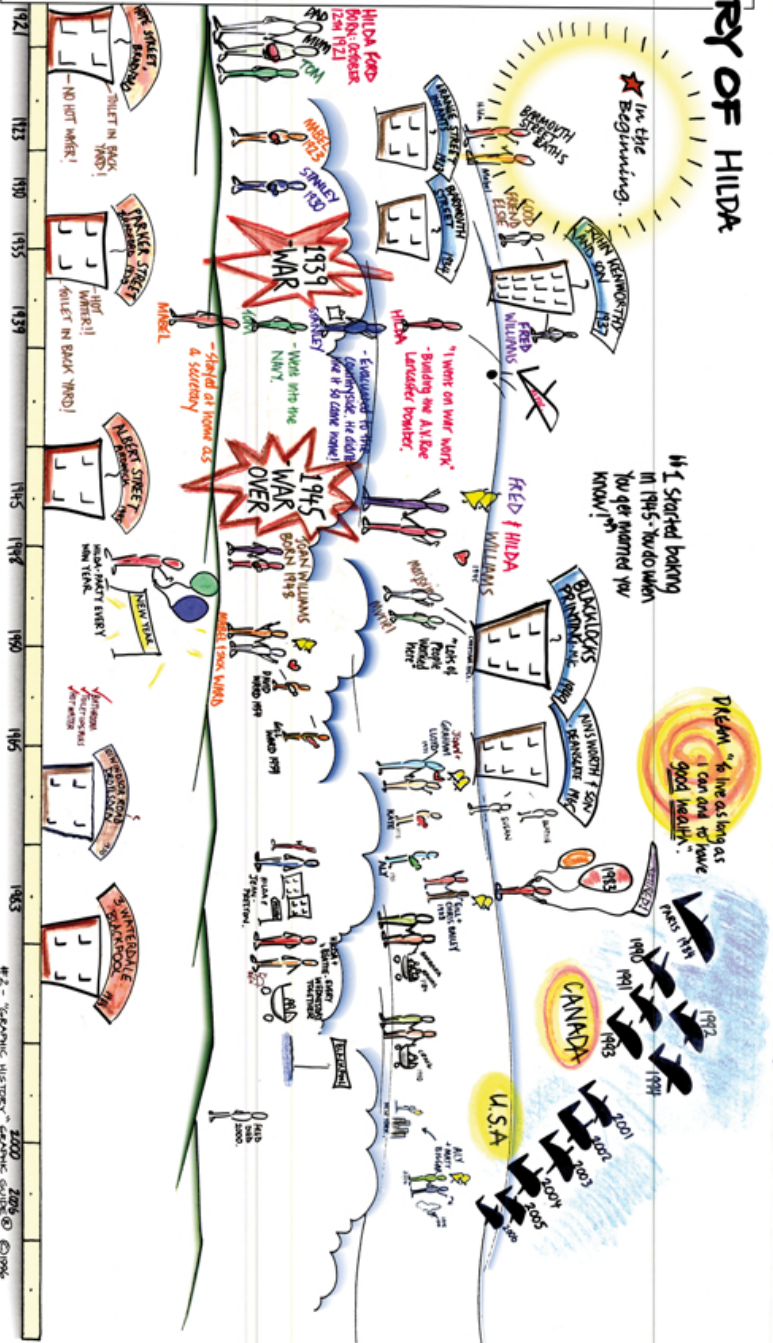
DATELINE

1921 1923 1930 1935 1939 1945 1948 1950 1965 1983 2000 2006

In the Beginning...

Hi I started baking in 1945. You do what you get married you know?!

Dream "I live as long as I can and I have good health."





Hilda Williams

Hilda is an inspirational woman, who is proud to be 87 and living in her own home in Blackpool. You would only need to spend a brief amount of time with her to feel the joy for life she exudes.

A film buff, her knowledge of the movies right back to the 1930s is incredible. She has travelled widely visiting her daughter Joan and her family, as their work has meant they have lived in many different countries. Her latest holiday photos are from Hollywood.

Hilda was talking with her great-niece, Babs, about how the world has changed and her hopes and fears around getting older. What really frightened her was that her memory wasn't as good as it used to be and that;

"Some day I may not remember what a great life I have lived so far."

Babs and Hilda decided to spend a few hours together to capture Hilda's life on a graphic history map. This was the start, and now they are scanning in family photos to create a family history book as well.

Alice Peacock

Alice used to work in the residential home where she now lives. The imposing house, Millbrook, used to belong to a mill owner, and Alice was the nanny to his children. Once the children had grown, she became the housekeeper and cook. She was a well-known local character, always at the heart of St. James' Church community. She is great company and has always loved to chat with other people, showing a real interest in what they have to say. Alice is delighted when staff, visitors and the people she lives with at the home chat with her and she loves to be acknowledged as people walk by, even if that means saying hello a number

"We knew so little of this information - especially about Alice's past. Who would have thought Alice was a keen birdwatcher and rambler? She has lived here almost 6 years, and all that time we didn't know. I've learnt so much about her by using this approach. It's just brilliant. It has given us a chance to step aside, learn real things about people and what changes they want to make in how they live." A staff member

of times as Alice will forget that you have already spoken to her.

Alice looks forward to visits from her brother Jim and his wife Agnes. June, a friend, brings her the church newsletter each month. As she struggles to read more than the odd sentence on her own, she loves to sit and have somebody read through it with her.

Alice uses her zimmer frame now and again to take short walks around the home. Sometimes the other people she lives with tell her to sit down, which really upsets her.

She sometimes becomes very anxious, believing that her mother is still alive and waiting at home for her. At these times, Alice gets very agitated, as she thinks her mother will be worried about where she is and vexed with Alice when she gets home. During these periods of confusion Alice will wander about the home trying to open

the doors to get out to go home to her Mum. Staff try to calm Alice by asking if she would like to go out for a walk, have a bath or sit and chat awhile.

Alice sometimes believes the other residents are people she has known in the past and will talk to them as if they are. This seems to reassure Alice.

The staff and someone who enjoyed drawing worked with Alice to create a picture of her past (a graphic history) and some of what is important to her. It's up on the wall now.

"It brightens my day to have people sit and ask me about my picture. I love talking about Millbrook and telling my many tales," says Alice.

The picture gives people clues about her past, so that they can talk with Alice and ask her about it.



How can this tool be used?

Assessment and care plans

Histories can be used at the beginning of any assessment so that people can see the person in the context of their own history and really get to know their life story.

First contact with a new service, group or support worker/team

In this way, histories can be seen as a next step on from Appreciation - knowing what people like and admire about someone can easily lead onto discussions about that person's life story, and what has shaped and influenced them. It can also offer insights into why what is important to someone is so important in their life.

Histories then are a powerful tool for building relationships and knowing whether something might work in terms of support or care arrangements, and therefore enable that person to have a good life. Histories are particularly helpful when a person is likely to have ongoing contact or support from someone or a service rather than a one-off interaction.

Reviews

Histories can be referred to as part of a review, to give a flavour of who the person is. Again, it contributes to seeing a complete picture of the person.

On moving to a care home

Moving to a care home or other form of supported accommodation can be a traumatic experience for many different reasons. Histories can help staff and others working in or visiting that home to get to know someone well. Using visual aids and prompts can bring these life stories alive. Having framed photos, pictures, framed family trees, scrapbooks to share are great ways to personalise people's living areas. People could use these to introduce themselves to new members of staff. Their past can also offer clues about what may be important to the person now. Involving family members and friends in sharing these stories, and providing photos and momentos to build this bigger picture is also a good way of ensuring they continue to have strong and positive relationships with the person who has moved to the home. Asking different family members to share their versions of family history can also bring people closer together in order to support someone through this transition.



In focus groups and research projects

Capturing personal and collective histories can also offer important insights into how services and wider systems of support can be better designed and delivered - whether these are formal systems (such as health and social care) or more informal networks and local community support such as groups, clubs, volunteer networks and so on. Asking local older people to share their histories (using clear and transparent guides that explain what is being asked and why) for example, as part of an 'appreciative inquiry' into what is working well in a local area, can offer valuable explanations as to why some services are used and are effective and others are not. It can also be used in more discrete settings e.g. care homes or day centres to understand how people came to be there, and why they think they are there. This can be important in two ways: it helps staff to understand the older person's present circumstances by getting to know their past; and it can help the older person in their move to a new place or home environment.

Person Centred Thinking Tool 6

Wishing

What do you wish for? Is this any different to what older people wish for? A project in South Oxfordshire asked a number of older people about their wishes and dreams as part of the Circles work described in the Introduction. The Oxford circles and wishes project, run by the Older People's Programme with Age Concern Oxfordshire, asked people in group settings (day care centres, lunch clubs and social clubs) what they wished for and what they thought it would take to make it happen. We did this because we wanted to find different ways in which interested organisations and individuals could adapt the Circles of Support approach to suit their own situations. Many people had told us that they didn't want or need to explore other aspects of person centred planning, but they were keen to share and explore their own personal goals and dreams - their wishes.

A session on wishes

Facilitators from the Older Peoples Programme ran a session with each of the groups on wishes, and then kept in touch with the club organisers afterwards to give them some support and ideas to carry this forward. There were between 15 to 20 people at each of these sessions. Many of those attending these clubs had disabilities and illnesses (including severe arthritis, Parkinson's Disease, depression, a dementia or sensory impairment) which both they and others involved in their support, had assumed had stopped them from dreaming or pursuing their wishes. Others felt it was 'just their age'.

Our conversations about wishes revealed a different picture.

The wishes we were told

Overall, we asked around 80 older people about their wishes, from five different 'clubs' and groups. Only a few people had no wish that they wanted to share with us. Of these, two could not think of anything because:

"My time is full doing different things - I'm fully occupied"

"My days are full with committee meetings, line dancing, bowls and Friday Club - weekends my family visit."

But most people had two or three wishes they could think of straight away. Some people needed a bit more of a chat before thinking of something - whether with us, or with another club member, or the club organiser or volunteers.

The wishes we were told are grouped under 11 general headings. This list of wishes includes those shared by the OPP team as well as any shared by the clubs' staff and volunteers. We've included these wishes because, whilst we know

which is which, we think that only some of these stand out as being obviously the wishes of younger or older people.

Interestingly, although some wishes might well cost some money to achieve, only two people talked specifically about goods they wished they owned, or could buy:

"I'd like a pair of amber earrings"

"Find Cadbury's Old Jamaican chocolate bar, as I can't buy this in the shops any more".

Our reactions

Our reactions to what we are told are critical. We wondered whether many of us are in fact too quick to write off an older person's wish, because either:

- We are worried about the risks involved (sometimes without understanding what's involved at all!) or
- It's not what we'd do, or
- We'd love it to happen as well - but life isn't fair so why expect to have this, or
- We dismiss it because we've heard it all before, or
- We don't think that's what that older person should be doing.

1. Trips, visits and holidays

- Visit a local factory to see how something (anything) is made
- A day out or trip to: (these included) Lourdes, York, London, Bath, Weymouth,
- Have a family day together
- Go on an occasional boat trip
- Go to the theatre in London on a Saturday night with someone
- Have a helicopter trip
- Go on a hot air balloon ride
- Revisit Arizona
- Go down a particular local walk, through a nature reserve
- Visit the chocolate factory at Cadbury World
- Visit a local garden centre
- Go to Cyprus
- Go on a world cruise
- Visit the Eden project
- It would be lovely to visit the Holy Land again
- I would like to take the train from America to Canada and go through the Rockies
- Go in a glider
- Watch stock car racing
- To be taken to one of the best and biggest hotels and watch all the top chefs at work
- To go out in my electric scooter more, to get the courage to cross the roads. At the moment it gets used about once a year
- Go to a horse racing event or a gymkhana



2. Do it again

- Ride on the back of a big motorbike
- Try cycling again, and have a cycling holiday
- Work on a pantomime
- Go to art classes

3. New skills

- Master a PC and also text messaging
- I would love to be able to mend punctures and generally maintain my bikes (that's the downside of always having brothers, boyfriends and finally a long suffering husband doing it for 50 years - how I wish I had taken notice)
- Look into my family tree and find out about all my family

4. Creative arts

- Make a kite, then fly it
- Take some photographs of the wooden flowers I collect
- Read more poetry, and write some too
- Read Charlotte Bronte again, and share this with someone
- I wish I had time to learn to paint well (paint pictures, not the walls)
- To visit the Globe Theatre and see a play there
- Attend a concert for older people where the players do not assume that we want to listen to music from the First World War
- Do more bead weaving
- To write a book - it's all in my head
- I would like to go to a Bournemouth Symphony Orchestra concert
- I should put my life story into print, having led a most interesting one - as a police

woman during the war and then travelling all over the world with my service man husband, it is difficult to start, especially as I now have Parkinson's disease and find it difficult to write

5. Things to do at the club:

- Hear a guest speaker

6. Living arrangements

- Live with Sally (daughter)
- I should make up my mind to join my two daughters and their families in the USA. Should I leave my friends and my British way of life to be with my American families? I wish I knew!
- Bungalow in the Lake District - country retreat
- Have a kitten again

7. Church

- Go back to C of E church
- Go to church

8. Luxury

- Have a massage on my neck and shoulders
- Please myself, be a lady of leisure and indulge myself
- Personal get fit trainer, chef and chauffeur

9. Fitness and health

- Learn to jive and Tango
- Walk the mountains in Wales again
- To have good health again
- Be able to walk about without fearing I'll fall
- Go to classes and get really good at Foxtrot, Rumba, Cha Cha Cha, Rumba
- To find out if the disabled

swimming club is still operating

- I would really love to be able to learn to swim, without being scared of the water
- It would be lovely to have a ramble on the Cumbrian Fells
- For someone to walk round Farlington Marsh with me on a [bright, sunny] day like today
- Learn to swim

10. People

- Meet up with a group of people I knew 20 years ago
- To have good neighbours and friends
- To see more of my friends
- Talk to Patrick Moore - he's so interesting, I miss going out to the local Observatory to see the sky at night

11. Life dreams

- Buy my own place
- Have enough money to give some to charity
- Have a lot of money to treat my family as they have been very good to me
- To be more positive instead of not being able to make a decision
- My dream would be to run a baby wear shop
- Go to South Africa to work with the children who are orphaned and who have Aids and are homeless
- Win the lottery and take it abroad to work with deprived people.



It's exceptionally easy for us all to believe that we all behave impeccably all the time, and never get any of this wrong. If only it were that simple. Most of us probably get this wrong at least some of the time - including those of us who know (or ought to know) better.

Here are some examples

In April 2005, we held a 'sounding board' seminar to which we invited a small number of key people nationally, who are interested in improving services for older people and in person centred approaches. When we mentioned that lots of people had the wish to go in a hot air balloon, one person said; "Not that old chestnut again."

At the same seminar, although we'd talked about a wide range of wishes (including the people who were looking into Voluntary Services Overseas, as they wanted to do voluntary work abroad), another person lamented over how limited older people's ambitions and goals are. At one of our Advisory Group meetings, we also heard this same view.

There is no doubt that we did not hear every single wish held by all the older people we met. But the ones we heard were genuinely held. If these are 'old

chestnuts', or they fall short of the sorts of dreams and ambitions we believe we have for ourselves, we shouldn't let our disappointments cloud our responses to their dreams. In other words, it might well be an old chestnut - but it's their old chestnut, and that's what matters.

Setting up false expectations

One issue that we heard a lot from people across the sites was in essence an objection to asking the question at all. It can be paraphrased as:

"You shouldn't ask because if you know you can't deliver, you've given someone false hope by setting up their expectations"

This seemed to be based on an assumption that we think we must fulfil everything if we are asking about it. So, if we ask, that's because we're going to deliver the wish. But when we won't be delivering the wish, therefore, we shouldn't ask the question.

This belief seems to us to be fundamentally tied up with the last 12 years of social care practice, since the community care reforms of 1993. We are used now to the idea that there

are limited funds and therefore limited opportunities. We are well versed in applying eligibility criteria, and in telling people they don't qualify for support.

What is it about us that we come to assume that we have to fulfil everything for an older person - and so leads us to avoid asking about any aspect of life where we think we can't do this? If your friend says they want to go on a world cruise next year it's highly unlikely you'll rush out to raise the money to pay for it, organise their health jabs, pack their swimsuit, present them with the tickets and physically escort them on board.

But there's every chance you'll show a great interest in their plans, ask them how arrangements are going, keep an eye out for articles and bits of information that might be of help or interest to them, ask them to send you a postcard, and then look at their photographs and home video/ DVD on their return.

This approach is about doing a little bit of both - a bit of practical help, and a bit of encouragement and interest. How much of each will vary from person to person, and from situation to situation. But this is not the equivalent of your paying for and sorting out every aspect of your friend's cruise.

There is another important aspect to this. As you're not expected to deliver the whole wish, try not to take over. This approach isn't about helping you feel better because you 'did' something (i.e. you sorted it all out), it's about supporting someone else to play as big a part as they can in achieving their wish, in part because:

- That's what treating an adult like an adult means.
- If the person can be encouraged by their own efforts, they may begin to tackle more for themselves.

Wherever possible, you should avoid creating the dependency on you to sort everything out. This means saying 'well done', just as you would to anyone you know who's doing something that might be difficult for them.

This is also why this is an approach and not a service.

Achieving the wishes

Some people, when asked, already had the contacts they needed to make their wish come true - but they weren't doing anything about it. What seemed to help them was talking to someone who was taking an interest and encouraging them.

In each case, the only question we had asked to start this part of the conversation going was:

- What would you need to do to make this happen?

Molly James - a visit to the Philippines

A good example was a woman whose wish was to go to the Philippines with her family. She had enough savings for a flight; her Philippine daughter-in-law went every year to stay with her own family and took her children. They were always inviting me to go over as well, so there would be no accommodation costs. She said:

"I've been saying for ages I'll do it, but that's definite. I'm going to ring my daughter-in-law tonight and tell her 'Book the tickets straight away and count me in!'"

Vera Barnham - a horse event

A woman who used to go to horse racing with her husband, said she would like to go again. Her son has a share in a race horse so she would ask her family if they would take her to see it race, or take her to see her granddaughter at a gymkhana.

Janet Barnes - a hot air balloon ride

One of the (several) people who wanted to go on a hot air balloon ride had already been on one before, organised by her son. She decided to ask him if she could go again, as:

"They're always asking me what I'd like for my birthday and Christmas, and I can never think of anything to ask for. If it's a lot of money maybe they could all chip in, or it could be my present for both. I don't need any more talc, that's for sure!"

She said it wouldn't have occurred to her to ask for something like that if we hadn't been asking the question about wishes that day.



Tom Mills - going on a cruise

One person who wanted to take a cruise to about 3 different countries, wrote:

"I am selling my house this year so feel this may well come true"

Of course, not everyone has money, or family, to help achieve his or her wishes. Nor does everyone feel well enough to do precisely what he or she might like:

Ron Armstrong - discovering the Masai Mara

A man with a mild form of dementia said his wish was to go to see the Masai Mara - but he didn't think he was well enough to travel that far. Later that day, he came up with his own solution: he would like a day out at Longleat Safari Park, because his wish is to see African animals in the open.

Tony Roberts - in touch with nature again

A retired gamekeeper and a keen walker in the past, a man now aged 90, said he would like to follow a particular local walk through a nature reserve. The club's deputy manager already knew the current gamekeeper of the estate through which most of the walk passes. She asked the gamekeeper about the possibility of using his Land Rover to take this man along the route. He said he would be delighted to help. She gave the gamekeeper's telephone number to the man, who is happy to make the call as this means he can arrange it to suit him. Separately, she heard that his daughter also knows he is to phone; so two of the people in this man's circle (or network) have been taking an interest and encouraging him to make the call, and are awaiting news that he has completed the "walk".



When wishes aren't achieved

Some people may not be willing or able to achieve their wishes. One woman we met said she would love to have a massage and learn to swim, but she "didn't have the guts". She found ordinary life hard enough without adding something extra that she felt sure would make her more anxious. But she liked the idea of the wishes.

Another woman said she would love to get all her family together but, as this would mean 17 people, she didn't feel she would cope. She was adamant that no one was to mention this to her family, as she knew they would then sort it out but that although she loved the idea, she would hate the reality. She said she wanted it to stay as her daydream

A third woman told an interesting variation: the minute she mentions to her daughter that she'd like to do something, it's organised for her - a trip to Dublin and an afternoon tea at a posh hotel were two recent examples. As a result, she is careful not to mention (even in passing) that there's something she'd like to do: she loves these events, but thinks her daughter does too much for her and doesn't want to add to this if she can avoid it.

We shouldn't let the fact that something might not work out stop us trying things. Life really is like that sometimes. If it helps you, think of examples in your own life where something didn't work out - what did you do? Did you really stop trying anything ever again? Be clear whether you were the stumbling block and, if you were, either find someone else who will be able to support the person better than you did or change your approach and ask the person if you might try again. If it doesn't work but there's nothing that could have been done to make it possible, try not to write off the whole approach.

Older people's top tips

At two of the clubs, we asked those present for their 'top tips' to other older people on how to achieve their wishes. This is what they said you need:

- Enough money.
- Enough confidence.
- To tell someone who might be able to help.
- Ask someone else - would they like to do it too? Work on it together - or do they know someone else?
- To find out different or new ways of doing something or other ways of going about things.

On the money front, these were some additional tips:

- Ask your family (or whoever else buys you presents) if something could be for Christmas or birthday or both.
- Think of an alternative that would cost less.
- Team up with others so you can share and spread the costs.
- Save up, and look for discounts.

Check your own assumptions: does your age really get in the way of you doing something? Make sure you find out before reaching your decision. Many people had told us that they didn't want or need to explore other aspects of person centred planning, but they were keen to share and explore their own personal goals and dreams - their wishes.

Summary of how wishes and wishing can be used

Asking someone about their wishes, and/or listening carefully to what is said in general conversation (which might reveal these wishes) can:

- Help to personalize the support that someone receives in small but vitally important

ways for that person. Often what people share are not big things, but important ways of doing things, past interests and friendships that they want to renew, or skills they want to develop. If costs are involved, they may well be personal expenses, and this can help to identify the priorities that person wants to focus on in order to have a good quality of life (e.g. paying for a taxi to go and visit a friend, or arrange a lift with someone else).

- Help to enrich someone's life and increase their control over what happens on a daily or weekly basis – moving their experience from one of surviving to thriving in a relatively short space of time. This can be especially important if someone is living in a communal setting such as a care home or other supported accommodation, where everything is organised for you and you therefore have little control over day to day decisions.
- Identify shared interests between two or more people – and therefore forge new friendships and networks. This can be particularly important if someone's network has diminished over time, or suddenly.

- Be part of a strategy for coping or living with depression or increasing low mood, through finding the things that brighten someone's day, or motivates them to get out and about and do the things they used to do, or always wanted to do.
- Help with decision making and building confidence in problem solving: for example in making wishes happen and working with others, or on your own, to make this work.

the one person who will ever hear this wish - and you may only be told once - then if you miss it, the wish may never surface again.

In all of this, it's important to remember that if we don't ask, we may never hear about someone else's wishes. We might not ask if we are worried that the person will think we are going to sort it all out for them -and we don't want to have to do this or don't have time or other resources at hand. We often forget to think who else might be able to help - including the person themselves. It may not occur to us to ask, especially if that's not 'the reason' we're talking to the person. The way we ask is also important, as is the way we respond to what we're told.

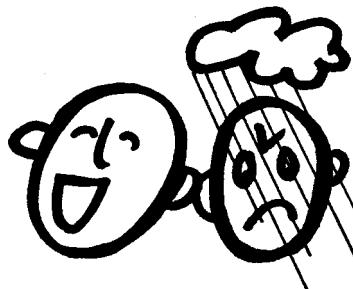
We also need to pay attention to what is being said in general conversation, and how we're being told something. You may be being told a wish. If you are

Person Centred Thinking Tool 7

Good days and bad days

We all have good days and bad days. What amounts to a good day for you may equate to someone else's bad day. Your good day may start with listening to hip-hop music as you get up. For others, anything other than the soothing tones of classical music or catching up with the news would be the beginning of a bad day. Many older people (those in hospital, those attending or receiving services on a regular basis, and those who live in communal settings) have been subjected to other people's choice of morning music, with little thought about the impact of this.

One of the ways to discover how best to support someone is to ask about their good days and their bad days. The staff who support Alice spent time thinking about what makes a good day and a bad day for Alice. They used this to identify the best ways to support her, so that she has more good days.





Alice Peacock

Alice has an ever ready smile. She is a gentle woman, who lives in a residential home. She never complains. This makes it more challenging to discover what a bad day looks like, so staff based their account of this on when they have seen Alice looking sad or distressed. Here's their list of what makes a good day for Alice.

What makes a good day for Alice?

- People taking the time to chat with her.
- Having visitors from church.
- Having flowers in a vase in her bedroom.
- Having chocolates with soft fillings to eat.
- Jim and Edith (her brother and his wife) visiting.
- June bringing the church newsletter and somebody

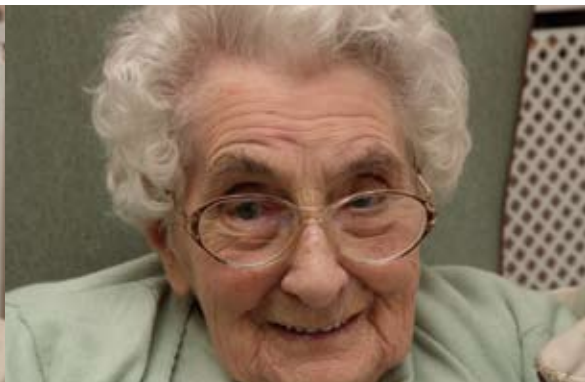
sitting and reading through it with her.

- Going outside for a short walk if she wants to.
- A bath with bubbles.

What makes a bad day for Alice?

- Feeling confused and worried when she believes her mother is waiting at home for her and she cannot get out of the front door.
- Being afraid her mother will be very vexed with her for not going home.
- Wandering around the home in a state of confusion.
- Being hot, flushed and breathless.
- Nobody chatting to her.

From this information, and from talking to Jim, Edith and June, the staff developed the list of what is important to Alice



Important to Alice

- Living in the Millbrook area
- see Alice's graphic history.
Her whole life centres around living in Millbrook.
- To have company and live with other people who like her. She will say: 'I'm all right here with the gang' - meaning the other people who live at the home.
- To chat with staff and the other residents.
- To see June each month, and for June to bring her the church newsletter.
- To be able to go outside for a walk whenever she wants to.
- To see Jim and Edith every week.
- To hug people she cares about.
- To have fresh flowers in her bedroom all the time.
- To have soft centred chocolate and sweets when she wants them.

- For staff to acknowledge Alice each time they pass by her.
- To have a bath with bubbles in and having water poured over her back at least three times a week.

The staff separated what matters to Alice from the best ways to support her. This included information that was not just about Alice's good and bad days, but also what they knew needed to happen to keep Alice healthy, safe and well

How best to support Alice

- Ensure she wears her built-up slippers.
- Read the church newsletter with her; she struggles to read it alone. Share her enthusiasm and pleasure in hearing what is happening within the church community, of which she was once at the heart.
- Always acknowledge Alice. She will beam at you and probably say, "Eeh, well, fancy

seeing you here.” She will then laugh. Have a chat with her, be interested in what she has to say. She will tell you so much about her life. Ask her to show you her history map – she will enjoy telling you her tales. Alice was a keen birdwatcher in the past; she may like talking about it.

- When Alice is having meat in her meals, it must be cooked until very tender.
- Alice struggles to eat fruit with skin on such as grapes, but enjoys bananas and tinned fruit.
- Alice will almost always say hello when you walk by her. Always acknowledge her, as she will forget that you have already said hello.
- Be aware that Alice may be a little low once Jim and Edith leave after a visit
- When you are in the room and Alice says, “Oy, oy, oy” she wants you to acknowledge her and have a chat.
- If Alice’s glasses have slipped down her nose, ask her if she would like you to push them up for her.

When Alice is confused, she is more likely to have a bad day, so staff added a separate section on how to support Alice then.

How best to support Alice when she is confused

- If she becomes breathless, her face is flushed and she feels hot, help Alice take her blanket off her knee and take her cardigan off.
- If she is looking for her, do not remind Alice that her mother is no longer alive as this will distress her further. Instead, try to comfort Alice by sitting and chatting with her. She will often think staff are people from her past and enjoys chatting away to them. This will distract her from trying to get out of the front door to get home to her mother. She will become more and more anxious that her mother doesn’t know where she is and she will be vexed with Alice when she gets home. Good support would mean taking Alice’s mind off the subject and just being with her, chatting and listening to her.
- Sometimes, when she is worried her mother is searching for her, a bubble bath helps Alice to relax.
- Showing Alice books with pictures of birds may take her mind off her anxieties and calm her.
- Ask if she wants to go outside for a walk. She find this

relaxing and will soon be ready for a rest and a cup of tea or coffee.

How can this tool be useful?

Exploring good days and bad days can:

- Help us learn what needs to be present and absent in a person's life.
- Help us learn what is important to a person and how to best support them.
- Tell us who the person has more good days with, who best supports them, and may identify the characteristics the person wants in these people.
- Provide information to people who do not know the person well. Staff turnover means that information gets lost, which is all the more reason for recording it.
- Enable people to make changes in their own life to help them have more good days.

This information can be used to inform assessments, care plans and support plans. It can also be used in reviews to better understand how to support people in the future.

It can be used to frame questions and discussions about specific treatment plans - for example to understand how treatments, equipment or other aids and adaptations are affecting someone's health and wellbeing.

But it is also a really useful tool for people to use on their own as well as with others. However this is used, it must be led by the older person and any record of these discussions must reflect how they define 'good day' and 'bad day'.



Person Centred Thinking Tool 8

Working/not working

For each of us, there are areas of our life that are working well and areas that are not working, that we would like to change. Simply asking an older person what is working and not working in their life tells us so much. This information may be used to change what can be changed and to help us understand what really matters to people.

Beatrice Kelly

Beatrice broke her hip in a fall on some ice 15 years ago. This forced her to leave her home and she now lives at Tree Lodge.

She is dignified and elegant. She was a successful career woman. A former headteacher, she later worked within Salford's education department, overseeing standards in all secondary schools in the authority.

Beatrice will talk about the great sense of loss she feels at no longer being involved with community and how she misses having her own front door. She hates the locked doors at Tree Lodge, which stop her getting out. She finds the temperature in the home too high, which makes her feel uncomfortable. She also struggles with having to eat at set times and feels this inflexibility is unjust.

Beatrice talks of her frustration at not being able to get around easily. She hates the zimmer frame and, due to health and safety

regulations, staff are not allowed to let Beatrice link arms with them for support. She would love to walk down to the library, a short walk from the home, but has to rely on the mobile service - which she occasionally misses if she is having an afternoon nap when they call. She spends a lot of time knitting. She has always enjoyed knitting her own clothes but rarely has the opportunity to get out shopping for patterns. Beatrice says;

"I was one hell of a shopper in my day, but don't get chance anymore. I miss my country walks, too. I was a great rambler."

Although Beatrice says she has come to terms with having to move out of her own beautiful house to live in Tree Lodge, she says,

"After all these years, I still really miss being able to shut my front door, close the curtains and settle down for the evening to do as I please."

She does, however, have things she enjoys at Tree Lodge. She enjoys sitting in her room at the home in the evenings and reading her newspaper or watching TV

- especially Coronation Street and Emmerdale. Beatrice enjoys reading. Bernard Cornwell is her favourite author, although she says, "I'll read just about any fiction."

A great frustration for Beatrice is that she is unable to wash her own clothes and, in her view, the home's laundry service leaves a lot to be desired. She also struggles with the amount of support she requires to look after herself physically. Beatrice feels terribly undermined when staff she doesn't know turn up on shift and support her to the toilet, with bathing, dressing and undressing.

"I feel defeated, it feels like nobody's listening when I tell staff how unhappy I am about this." Beatrice asks herself, "What have I come to when a stranger is putting me on the toilet?"

Even worse for Beatrice is when some staff do not wait at the door while she uses the toilet, but go away and do something else.

"Then they come back to take me off the toilet when they it suits them."

Important To Beatrice

- To be called Beatrice, not Beattie.
- To choose when I eat. I like my tea around 6pm, not 4.30 pm, and that I watch TV whilst I eat.
- To read in bed for an hour before sleeping
 - any crime fiction is my favourite.
- To have my cotton blouses starched and ironed.
- Watching my soap operas. Coronation Street and Emmerdale are my favourites.
- I love knitting my own clothes.
- My photograph albums of my son George growing up and late husband Ben.
- To chat with people about my life, especially my last job before retiring, when I was an Education Inspector.
- I must go out once a week shopping. I especially enjoy choosing my own knitting patterns.
- To have my morning newspaper every day, the Mail and Mail on Sunday are my favourites.
- I love walking – anywhere these days, but where there are fields is my favourite.
- To feel fresh and not over heated.
- To wear my own clothes. I must not be dressed in other people's clothes. I hate this!

What those who know Beatrice say they like and admire about her

- Always has a kind word for everybody.
- A strong and gentle woman.
- Great integrity.
- The gentle way she sits and talks with me.
- Her determination.



How best to support Beatrice

- That only people I know well help me in the toilet and bathroom.
- Recognise my embarrassment at needing help in the bathroom and toilet; be sensitive & kind with me.
- Don't leave me on the toilet a long time.
- Wait at the door so I can call you when I am ready.
- Let me link you when I walk; I hate the zimmer.
- Heat my meals when I want them; don't tell me when I must eat.
- I like lots of cups of tea – not just at set times. Please make me one when I ask.
- Let me know if the mobile library service calls. If I am having a snooze, I miss them.

Beatrice

Sally, a new senior staff member, helped Beatrice to summarise what was working and not working for her. Sally also talked with staff, and captured what was working and not working from their perspectives. This is what she found:

What is working for Beatrice

- Reading her books at bedtime and having a variety to choose from.
- Watching the TV and never missing her soaps.
- Knitting.
- Having a daily newspaper delivered.

What is not working for Beatrice

- Not being able to go out for walks (has only been out twice in the last three months to buy her patterns).
- Not having someone to link her arm to support her for the 10 minute walk up to the library.
- Using the zimmer frame to walk.
- Having to eat meals at set times, with no flexibility each day.
- Staff calling her Beattie.

- That her family do not visit her.
- Her blouses not being starched.
- Always being too hot.
- Not being able to open windows.
- Having other people's clothes put on her and other people wearing her clothes.
- Having name tags on her clothes.
- Clothes being spoiled in the laundry.

What is working for the staff Team

- People's clothes being clearly name tagged.
- Beatrice eating at the same time as everybody else.
- Beatrice walking with her zimmer frame for support.
- Beatrice enjoying her books and TV programmes.
- Beatrice fitting in most of the time by eating her meals with other residents.
- The mobile library service
- Catching up on other jobs once Beatrice has been positioned on the toilet.
- Keeping the home warm for all the residents.

- Keeping windows closed so that nobody is caught in a draught.
- The laundry service coming in and taking the home's laundry each week.

What is not working for the staff team

- Her family not visiting.
- Beatrice asking for drinks and meals outside of regular times they are served.
- Having to go to the newsagents to pay for Beatrice's daily papers.
- Beatrice linking on to them for support when walking.
- Beatrice not liking new or agency staff members helping with her personal care.

Sally decided to explore what could be changed from the not working lists. Some things were easy - for example, making sure all staff called her Beatrice, not Beattie. She took the information and developed it into a one-page profile about what is important to Beatrice and the best ways to support her. It begins with what people like and admire about Beatrice.

Perspective	What's working	What's not working
people who live at the care home	Drinks at 7.00pm. Having a choice of drinks - coffee made with milk or water, tea, peppermint tea, a tot of whisky, hot chocolate, Horlicks. Having own cup-china, pint mug. Occasionally having cake, toast, jam sandwiches, hot cross buns or fruit cake.	No choice of snack - plain biscuit.
staff team	Drinks at 7.00pm	People not drinking, which may adversely affect their health. Limited snacks at suppertime. Nothing to offer people with diabetes at suppertime. Having to bring cakes, snacks in themselves to give people choice at supper.
Managers	Cook does not need more hours to provide extra food at supper-time.	Staff and people who live there are unhappy with choice of snack at supper.

Using working/not working at Oakwood House

We have also been using working not working at another care home. Steve Mycroft and Shelia Mannion own Oakwood House, a small care home in Tameside. They believe that there has long been a need for a change in cultural practices in many care homes for older people. Historically, there is a great emphasis on operational routines, rigid systems and care within restrictive boundaries. They think that the traditional and somewhat negative views and public portrayal of care homes for older people will become a thing of the past if people start to work in a person centred way .

"At Oakwood House we want to help break down traditional cultures of residential and nursing care settings. We want to use person centred approaches to look closely at the individual wants, needs and wishes of the people using our service, and ultimately, to find out what's really important to them."

Steve Mycroft and Shelia Mannion

Like other care homes, Oakwood House encourages people living there to create their own lifestyles and have a strong voice in how their services are provided in the future.

"We don't want people living here to have to fit in with organisational routines, and person centred thinking is helping us to scrutinise our own practices by listening to people's real experiences of living at Oakwood House"

They decided to start this process by looking at what is working and not working around supper time, from different perspectives. They had already looked at the drinks that people had available at supper time, and provide a wide selection, including tots of whisky. Now they wanted to see what else they could do to improve supper time.

Sheila and Steve are now working to extend the range of snacks at supper time on a daily basis. Their first action is to find out exactly what people would like, or find other creative ways to make this happen - including some people cooking the snacks themselves.

How can this tool be useful?

You can use this approach to:

- Help people step back and look at a situation – to see it and understand it from different perspectives, especially the older person's.
- Learn how a person wants their life to look and feel in comparison to what life is actually like right now.
- Help staff teams think about how to provide better support by seeing what is working and not working about their support now.
- Clarify what to build on and identify areas requiring action to change.
- Contribute to reviews - both to understand how things are going since changes have been made; but also to pick up issues and problems in the first place.
- Engage people (e.g. family members, neighbours etc) who are important to the older person in understanding what their life is like, and how they can contribute to making a difference to that person's life - often in very small and simple ways.
- Understand the impact of changes in someone's life, on that person's quality of

life and overall wellbeing.

For example changes in their health, sudden onset of a disability or impairment, bereavement or other loss (e.g. moving house, and people moving away).

- Help resolve problems and concerns to help reduce isolation and depression.
- Help people manage bouts of ill health and/or depression by developing their own personal tools and techniques for self reflection and problem solving.

Self directed support and support planning

Self directed support means having the support you want, the way you want it. A support plan is one way to describe how you want to live, how you want to be supported, and how you will spend your money (your own funds or an individual budget).

Derek is taking steps to make sure he has the support he needs in a way that makes sense to him.

Derek Hurst

Derek is 72 and lives in a care home in Portsmouth. He worked with the manager of his home, Kathryn to think about his life and his support.

Derek uses a wheelchair, following a below the knee amputation which restricted his mobility and confidence in getting out and about. He has since lived in local authority care homes (a number of years) and moved to his current home in 2001. He was born in Gosport, and like many local people was in the Navy between 1938 and 1962. After leaving the Navy he had many varied jobs including working as an electrician in a local factory, as a security guard and a driver.

He first moved to a care home following a serious accident, when his leg was severely burned in a fire at his flat, where he lived alone. When Derek did not turn up at his local pub as usual, the pub's landlady went to check that he was ok. Derek says he only remembers waking up in hospital - the landlady had found him and called an ambulance. He often says "she saved my life". One leg was



amputated, and he was told that he wasn't strong enough to have a prosthetic limb, so he now uses a wheelchair.

Derek's day to day life in the care home

Derek reads the newspaper everyday and watches television, enjoying snooker and quiz programmes. He particularly likes the company of a female resident with whom he sometimes shares morning coffee. He likes his room, and wants to stay living where he is. He gets upset about losing his leg, and says he sleeps a lot during the day because he is bored.

The first thing that Derek wanted to change was to be able to move more easily between his wheelchair and his bed. Kathryn said that she had no idea that this was important to Derek and she arranged for an OT to visit him, and show him some safe methods for doing this on his

own. Afterwards, Derek said he was finding this much easier, and the staff in the home said they did not have to help him so much.

His second goal was to return to the pub where he used to drink, because he wanted to see the landlady again, which he did after much discussion and some initial anxiety on the part of the care home and to some extent the pub landlady. Following a successful first visit - where Derek was delighted to be able to thank the landlady properly for helping him, after which he just wanted to sit and enjoy a quiet drink, chatting to other pub locals - Derek worked out how to afford more regular visits including taxi fares and drinking money. Like many older people who live in residential or nursing homes, he did not have control over his spending money, but through these visits, this gradually changed. Derek now knows how much money he has to spend, he looks after his

money, and he plans what he spends it on.

Derek had been married and divorced twice. He has three children, a son and daughter from his first marriage, and another daughter from his second marriage. His son visits him every couple of weeks or so, but he has not seen his younger daughter for 30 years. He last saw his older daughter a few years ago, when she visited him in hospital after his accident. He does not know where she lives now.

No one at the care home knew about Derek's marriages nor of his estranged daughters. After much discussion with his staff Derek decided that finding his daughters should be left to 'the experts' - in this case, the Salvation Army's.

Derek's life - then and now

Derek's life has changed with his regular visits to the pub where

he sees friends, occasional visits with his brother and the search for his daughters. He is more in control of his life, making decisions about arrangements and money and generally feeling very positive. The people in his life have expanded, from his son, brother and care staff to:

- The pub landlady.
- The barmaid.
- The regular taxi driver.
- Other drinkers at the pub.

It has also been quite a change for the care staff working with him. They know far more about Derek. They have also been challenged to think about the specific things an individual might want to do for which the more usual group response found in care homes (shared activities, communal meals etc) is not appropriate - and how to support someone to achieve more and more of this for themselves. The temptation

for staff to sort everything out was quite high. This may be a reflection on the way in which care home staff are used to describing their work as making sure that everything is done for you, so you don't have to worry. This approach, however kindly meant, may work to strip away any last vestiges of independence, and makes 'self directed support' less likely.

Being able to change and adapt your support is important. You can be in greater control of your service when you have control of your money, whether through self funding or through having an individual budget.

A framework for developing a support plan with older people

A crucial part of having an individual budget is deciding how to spend it to have the life that you want. The way to do this is by developing a support plan. This works whether your money is from an individual budget, or whether you are self funding and want to think about how to spend your own money.

A support plan helps people to think about how they want to spend their individual budget to help live the life they want. It has information that the local

authority needs to have to give them their money (individual budget).

Some people want help to develop their support plan. They can ask family and friends, or in some cases, an Independent Mental Capacity Act Advocate (IMCA) to help. There are other people who will help, for example care managers, social workers, people called person centred planning facilitators or advocates. Older people can also ask someone to do their plan with them if they choose.

The support plan belongs to the older person. Although developing a support plan does not always have to be linked to someone receiving an individual budget, anyone using an individual budget should always have a support plan.

A budget holder³ needs to see the support plan to check that it has all the information it needs, and will need to keep a copy of some of the information. A support plan should tell the budget holder what is important to the older person, what they want to change and what steps they are going to take to make these changes and how they plan to use their money to achieve this.

These questions are questions to help an older person, and their family or friends to think about their life. This is one approach to developing a support plan.

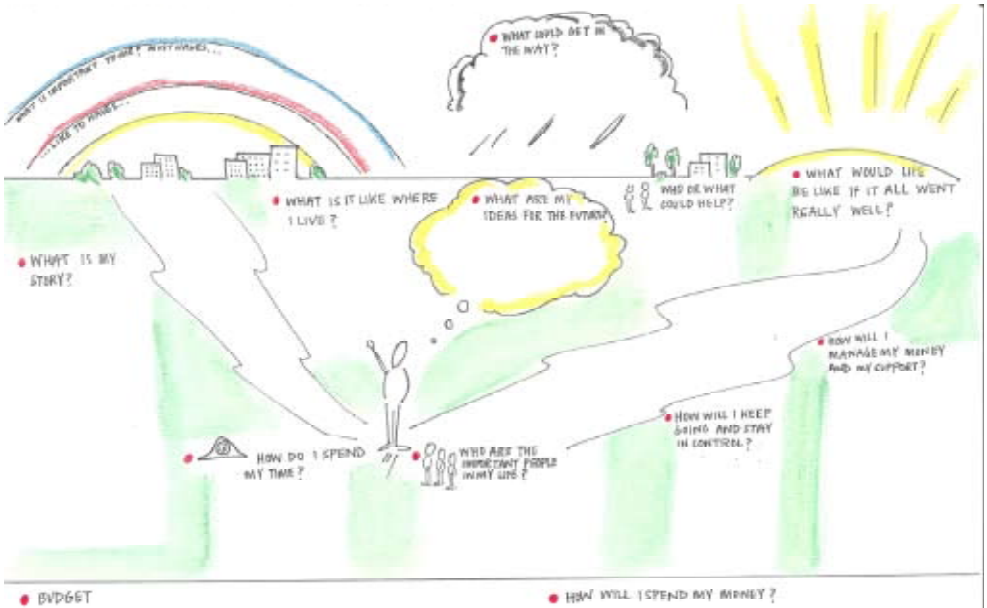
Question	Additional Prompt Questions
<p>How did you get where you are today?</p>	<p>Tell me about yourself? How are you today? Tell me what you are proud of, like family, work Who was in your life in the past?</p>
<p>Who is in your life now?</p>	
<p>What about where you live?</p>	<p>What time do you spend with others? What time do you spend on your own?</p>
<p>How do you spend your time?</p>	<p>What is a good day for you? What is a bad day for you?</p>
<p>What ideas do you have about how you would like your life to be?</p>	<p>Would you like to see and hear what other people have done or other examples of support plans? What matters to you? What is important to you? What do you miss that you do not do anymore? What would it take to get that back on track? How would you like your week to be? What do you want to change about your life? What do you want to keep the same?</p>

What are your ‘must haves’ and what are your ‘like to haves’?	
What is, or could get in the way?	How is your health? Is there anything that you need to leave or grieve for? What are you worried about?
What or who could help?	
What would life be like if all this went well?	Where do you want to be in 12 months time?
How are you going to use your money? What will you spend it on?	Provide information about the options (e.g. Direct Payment, indirect payment, care manager commissioning on your behalf, or an individual service fund) Do you know who to ask or where to go for advice?
How are you going to manage your money and your support/help?	Do you need any help in managing your money or managing your support? How do you want us to help you if there is a crisis? Do you want to have a contingency plan?
What are you going to do to make this happen?	

This document was developed with contributions from: Helen Sanderson, Carey Bamber, Helen Bowers, Pauline Doyle, Judith Whittam, and the Manchester, West Sussex, Bath and North East Somerset Individual Budget pilot sites.

Some people like to use big posters to capture their information, and we have developed one that people can put on the wall and fill in (see below). Some people want to develop support plans with other people who are doing the same thing. This can be done over two days and the process is called 'Planning Live'.

All of these ways work for different people. Some people write a few pages and stick a photo on the front. Older people are encouraged to choose what feels right for them. Their care manager should be able to help people to get the support they may need to do this properly.



Chris's story describes the difference that an individual budget can make

Chris's story

Mum, who is aged 80, has multiple physical and mental health issues including short term memory loss. Dad, who is 84, is registered blind and has physical and mental health issues including short term memory loss. They are a close couple that have been married for 60 years.

Although my father is the primary carer for my mother I provide significant and increasing support to them both. Social Services initially provided support through an agency. While this was OK, attendance to get Mum up in the morning varied between 9.00am and 12 noon, which they found difficult, as they were unable to plan things.

My mother was regularly booked into a residential care home to give dad much needed breaks. She hated being parted from my father, as with the exception of hospital stays, they had never been apart.

I heard about Individual Budgets and asked if my parents could be part of the Local Authority's pilot for older people. Following

acceptance on the pilot, we received a resource allocation based on Mum's existing package, and a small amount for my father to meet his increasing needs. I then developed a support plan with my parents and the rest of the family.

My parents decided that employing their own staff would be best. We wanted to pay good rates and Dad wanted time off from 'outsiders visiting'. We ended up agreeing that Mum's Personal Assistant (PA) would work more hours than agency workers previously had and that we could pay a decent rate if I provided support at the weekend. Instead of Mum going into residential care ("with all old people"), we arranged for my parents to visit a small hotel in Bournemouth, so they could have a break together. I arranged for a local agency to visit Mum at the hotel and to take her out in her wheelchair on a couple of afternoons. Friends took them down and brought them back in return for a good meal out. An additional grant was made available for equipment to reduce the risk of Mum falling.

These relatively small differences have made a huge difference to my parents and indeed for the whole family.

- Mum's PA now visits at a time that suits her.
 - She has a bath everyday which she loves as it helps ease her painful joints. She also has help with ironing and other tasks. The agency staff commissioned by social services were only allowed to undertake personal care, which put extra pressure on my father.
 - My mother's PA also takes her to the day centre instead of her having to wait for the bus, which came at different times and had to collect other people.
 - The PA's hours accrue when they go away so they can be used flexibly and provide support when one of them is unwell. Mum has had no falls during the night since the equipment was installed six months ago. Previously she fell about once a week.
 - My parents now enjoy regular breaks together and Dad has male company once a week to take him for a walk. He was used to exercise, but had lost his confidence following a bad fall. They go for a pint on the way home. His PA also helps do small DIY jobs that with the loss of his sight he is now unable to do.
 - The reduced falls require less visits to A&E
 - Now I have people around to help when things go wrong, which is great as I work full time.
- ¹ The six factors are: delivering services closer to home; early intervention and assessment to pick up support needs; management of long term conditions in the community; early supported discharge from hospital; access to hospital care when needed and quick access to specialist centres; partnerships with older people and their families.
 - ² The work described in each chapter was undertaken by a facilitator working with Helen Sanderson Associates or the Older Peoples Programme.
 - ³ The budget holder is the person who has the legal responsibility for allocating public money to people with support needs.



Final thoughts

We are working with people across the country to explore and develop this work, we hope to add to these stories and examples. We will share these on the following websites:

www.helensandersonassociates.co.uk

www.opp-uk.org.uk

the Centre for Policy on Ageing www.cpa.org.uk

the Care Services Improvement Partnership's (CSIP) Knowledge Community www.csip.org.uk

in Control www.in-control.org.uk

If you have material that you would like to share, about how person centred thinking and self directed support is making a difference, please send this to Gill Bailey on gill@helensandersonassociates.co.uk



The Older People's Programme (OPP)

Helen Bowers, Lorna Easterbrook, Alison Macadam and Cathy Smith all work for The Older People's Programme

The Older People's Programme works with local, regional and national partners across the UK to improve services and opportunities for older people; influence policy and practice; share learning and information about best practice; and support the continuous development of public services.

T. 01202 416032
www.opp-uk.org.uk



Helen Sanderson Associates

Helen Sanderson and Gill Bailey are part of Helen Sanderson Associates. Helen Sanderson Associates is a development, training and consultancy team. We work with people to change their lives, organisations and communities through person centred thinking and planning. We have teams in the UK, Australia and America.

Helen Sanderson Associates provides training in person centred thinking and support planning.

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