

Beyond life histories

9 practical
ways to deliver
personalisation
with people
with dementia

Helen Sanderson and Gill Bailey





About this ebook

Hello

Personalisation about people living with dementia – what is it all about?

If you are already providing good person-centred care, and have used life stories, and want to know how to extend this even further, I hope this ebook is useful to introduce you to 9 person-centred practices to deliver personalised support.

If you want to know what personalisation means in practice for people living with dementia, my hope is that this gives you day-to-day examples of what this means.

I hope that you find it helpful, and are interested in trying out some of these person-centred practices.

If you find it valuable, please share it with your friends and colleagues by using the options here.

All the best,



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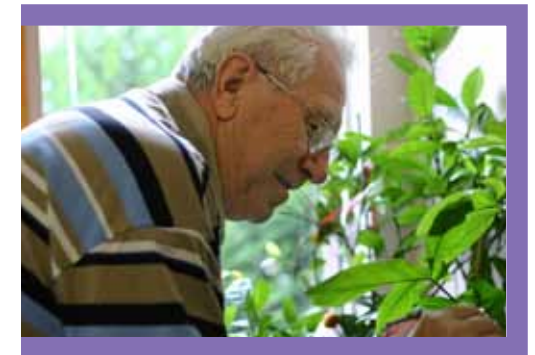
We all know that people living with dementia must be treated with dignity and that good services provide 'person-centred care'. We also know that in good care homes, staff spend time learning about the person's life history, and treat each person with respect.



You may have heard of the term ‘personalisation’ and wondered if it is the same as person-centred care and developing life histories for each person.

Personalisation builds on person-centred care. Personalisation means that as well as treating people with dignity and respect, we also strongly focus on helping people direct their own service and have as much choice and control in their life as possible. Instead of fitting people into existing services it means designing their service around them. People get the support they want and need, when they want it, in the way that they want it, at the time they want, delivered by the person they want. These are likely to be the services that people want to buy in the future.

Recording life stories is very important. Sometimes they are completed as part of the admission process and then filed away. Even where life stories are used well, they are not enough in themselves to deliver personalisation. One way to deliver personalisation is through personal budgets, where people get their budget directly (often as a direct payment) and use this to buy their services themselves. The government is piloting how to make this work in residential care homes as well. As well as personal budgets, there are 9 practical ways to deliver personalisation to people living with dementia, and in this e-book we introduce each one. They are evidence-based practices and the Department of Health recommend them in the guidance ‘Delivering Personalisation through Person-Centred Planning.’

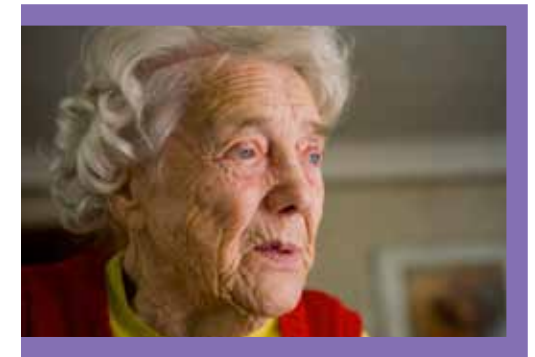


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How can you deliver personalisation for people who are experiencing dementia?

Lisa is the manager of Bruce Lodge, a care home for 43 people living with dementia. Staff already work hard at all the tasks that have to be done, and it was difficult to imagine how they could do more. Lisa wanted to see how they could deliver an even better service; a more personalised service, without extra staff or money. Lisa used all of the 9 ways we have described in this e-book, in her care home. It made a huge difference.

Bruce Lodge was a good care home before Lisa started to use these 9 ways to deliver personalisation. When people moved into Bruce Lodge they were allocated a key worker based on where their bedroom was in the building. Staff did a life history with the person and their family, and recorded likes and dislikes. Staff were busy all day getting jobs done but would try and sit and chat if they could. There is a residents' group and Lisa listens to what they have to say. People living at Bruce Lodge could decide which room they want to go in, and whether to take part in group activities.

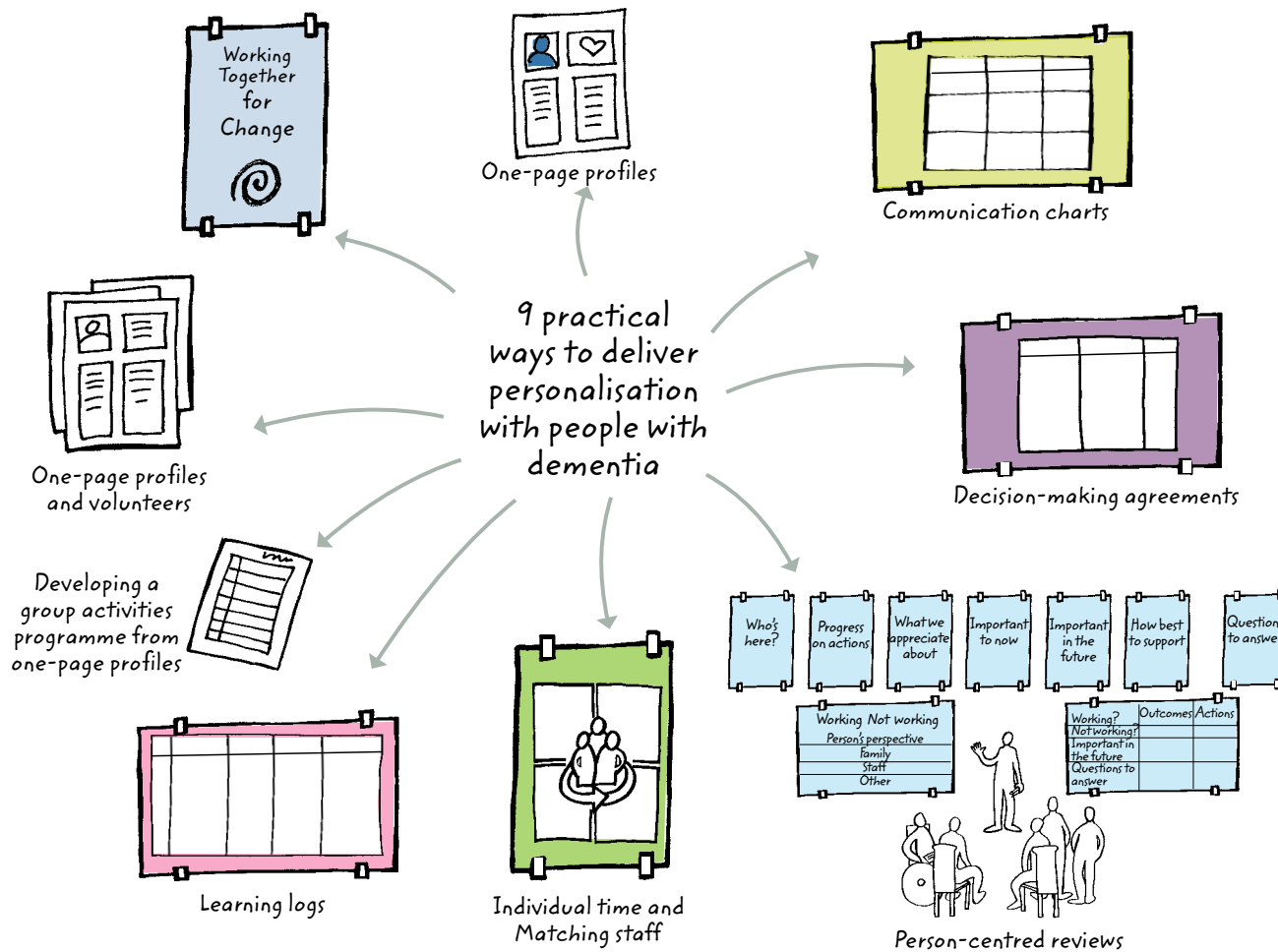


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This is not very different to the most expensive or very best care homes. The difference is mainly in the environment, activities, and hotel services. In these care homes there may be areas or rooms with themes from the past, and many things to pick up and look at. There may be a full-time activities co-ordinator offering a greater range of activities. There may be sophisticated dining rooms with menus and silver service. Although these are better 'hotel services' they don't necessarily deliver a more personalised service.

"I didn't think we could do any more than we were doing – but the difference that we made was amazing. We know each person better, they have more choice, and are doing a lot more things. The biggest surprise was the positive changes in the staff, who now go the extra mile with people." Lisa

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In this e-book we share the 9 practical ways to deliver personalisation that Lisa used to change Bruce Lodge.

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These are ways to:

- Make sure you know each person in detail – both what matters to them and how they want to be supported, so that you can provide personalised support.
- Know the specific ways that people communicate, so that all staff can consistently ‘hear’ what people are saying with their behaviour and words, to enable people to have the most choice they can about their life and service.
- Know how to support people to make more decisions, and be supported to make as many decisions as possible.
- Keep learning about the person and how to record this so that everyone uses this learning, so that support changes as the person changes.
- Allow people to choose or be matched to staff who share their interests.
- Help people to choose outcomes – and how they want to spend their time.
- Learn about and change what is not working for people, so that people shape and direct their service, even if they no longer communicate with words.
- Easily develop an activities programme that reflects everyone’s interests, so that the service offered is based on what is important to people.
- Work with volunteers differently and make sure they get good support, and to connect people within communities.
- Make sure that everyone’s opinion directly informs how the service develops (even if people can no longer talk).



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Delivering personalisation means person-centred care plus using person-centred practices. We are not saying that these are the only things you need to deliver a truly personalised service; you also need excellent leadership from managers, to work with staff in person-centred ways, and a focus on compassion. The examples that we use are from residential care, but we hope that you can see how they can be used in homecare as well. The person-centred practices that we introduce in this paper are one-page profiles, communication charts, decision-making agreements, matching support, learning logs, person-centred reviews and Working Together for Change. This is not new paperwork. We have seen organisations simply add these to existing care plans. These person-centred practices reflect different ways to have conversations, to learn about people and to support people to have more choice and control.

They also help to meet the essential standards required by CQC. We start with the first building block towards personalisation – a one-page profile.



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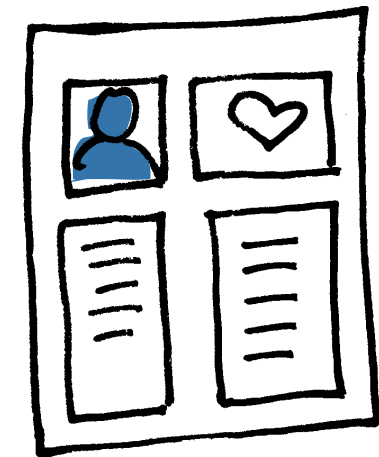
One-page profiles

Personalisation starts with the person; knowing who they are, what matters to them and how they want to be supported. A one-page profile is the foundation of personalisation. Without this it is easy for everyone to see the person's dementia first, and not the person. A one-page profile has 3 sections.

- 1 What people appreciate about the person (their gifts, strengths and characteristics).
- 2 What is important to them, from their perspective.
- 3 What good support looks like (what staff need to know and do).

Great care plans may include much of this information, but it is usually dispersed throughout the plan, amongst clinical information, assessments and reports. Life histories have good information about what the person has done in the past, but doing a life story does not replace detailed knowledge of what is important to someone now.

In Bruce Lodge each of the 43 people who live there have a one-page profile at the beginning of their care plan. They are like a job description for staff. They are developed through conversations, and an informal meeting with the person and their family, when people move in. Here is Chris':



Chris' one-page profile

What is important to Chris

- To be called Chris.
- Her daughter Sue, who visits each week, and Sue's husband Bill. Also Sue's dog Benjy.
- Her son, Rob Geoffrey, and Lorette his partner, who lives down South and visit mum when they come to stay with Sue, usually every 3 or 4 months.
- Kate, her eldest granddaughter, her husband Andre and Beth and Lucy their children, her granddaughter Sally and her husband Rodger, Molly and Cara her great-grandchildren who visit when they can.
- Rosemary and Elizabeth, her nieces, who visit when they can.
- Always having her handbag and her walking stick with her – never out of her reach.
- Having a sherry or a brandy with her friends, who live here, each evening.
- Going to New Brighton for the day. Chris grew up in Liverpool and has always loved New Brighton.
- Chris always loved going to the swimming baths.
- Chris loves to sort out and tidy up. Folding laundry, pairing socks, tidying drawers, drying up, putting cutlery and crockery away – NOT washing up though.
- Watching snooker and football on TV. Liverpool are her team. Chris always loved hockey too.
- Her faith, Church of England.
- Playing board games. Upwards is favourite. It is on top of Chris' wardrobe.
- Having a game of cards – Snap or Patience are always good. Chris needs some help when playing cards, but not Snap – she can play snap without help at all.
- Going out to garden centres. Chris loves flowers.
- Watching TV programmes such as Antiques Roadshow and Bargain Hunt.
- To always look nice.
- Adores cups of tea; milk and two saccharins.



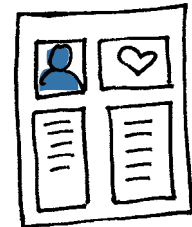
Chris

What people appreciate about Chris

Her creativity
 Wonderful dry sense of humour
 Her wink
 Solid determined woman
 Straight talker

How best to support Chris

- Chris will always respond well to warmth and friendliness from those supporting her.
- Chris puts crumpets, sandwiches, biscuits and other foods in her handbag as she has an anxiety she may run out of food and needs to keep a stock just in case. To support Chris well, discreetly remove any food which is inedible or likely to become so. You need to do this weekly.
- Chris does not eat much all at once but will have regular small meals – never refuse her when she comes for a meal (even if she has lost recollection that she has just eaten) as she only eats small amounts at a time. Monitor Chris' weight as she has gained some recently.
- Know what is on Chris' one-page profile around things that matter to her and initiate making these things happen.
- Be aware that initiating things with Chris is crucial to her wellbeing. She generally wouldn't get involved in things; cards, conversation, watching TV, unless you take the lead.
- Chris will often say 'no' if you ask if she would like to do a certain thing. It is better if you say 'let's go up to the café for a brew and a cake'. She then thoroughly enjoys herself.
- Always ensure Chris has her hearing aids in properly and that they are working.



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One-page profiles

Communication charts

Decision-making agreements

Person-centred reviews

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One-page profiles and volunteers

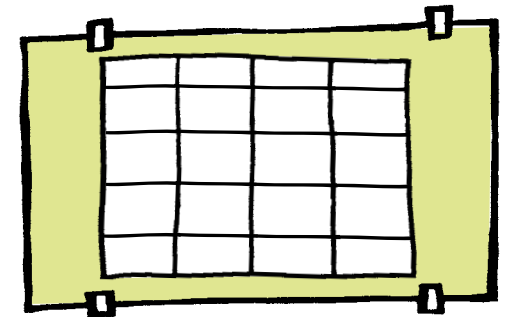
Working Together for Change

Communication charts

Personalisation means making sure that the person has as much choice and control in their lives as possible. The communication chart is a powerful way to record how someone communicates, with words and behaviour. Often behaviour that is described as 'challenging' is a result of staff not understanding what people are trying to communicate. These do not replace 'ABC' charts, which some organisations use. Often these are filled in and filed away. A communication chart is both a way to understand someone's communication, and a description of exactly what staff need to do, to enable people to be heard and to make choices.

Sometimes what people say and what they mean are different things, and a communication chart is a way to explore and record this. The communication chart has four columns. The first is 'at this time' and records the time of the day, or what is usually happening. The second is 'the person does or says this' and this is where we write what the person does to communicate. The third is 'we think it means' (what the person is communicating with this behaviour - our best guess). And the final column is 'and we should' - what the staff member should do, for example, how to reassure the person.

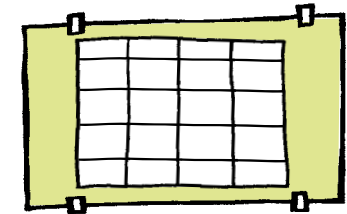
Most people at Bruce Lodge have a communication chart as part of their care plan.



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Doris' communication chart

At this time	Doris does this	We think it means	And we should
Anytime	Doris hangs handkerchiefs up around the lounge	She thinks it is Christmas and is putting decorations up	Ask what the celebration is - enjoy with her. Sit with her and go through her photograph albums which she loves to share.
Anytime	Covers teapot or similar with a handkerchief	She is thinking of Mass and the Eucharistic	Go through the book of minutes she kept from church meetings whilst listening to her CD of favourite hymns
Anytime	Lays newspapers or magazines on the breakfast bar and makes a cross on her lips	She is delivering the gospel reading at the altar	Sit quietly with her until she has finished
Anytime	Doris wants to see what is in the pocket of other people	She has run out of the lollipops she keeps in her pocket	Go to the shop with Doris to buy more - if that isn't possible there is a box in the office. Replenish her supply, 15 will usually last her a week



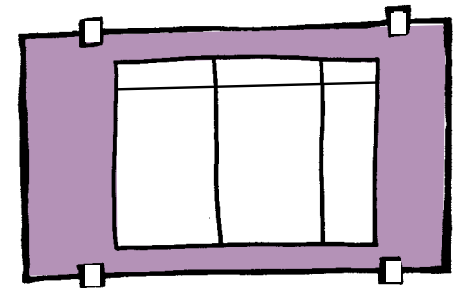
Decision-making agreements

Knowing how someone communicates is essential yet we need to do more to give people greater choice and control over their lives. How people make decisions, and how often, is related both to their ability (mental capacity) and their opportunities to make decisions. Mental capacity simply means the ability of an individual to make their own decisions. Many people living with dementia may lack the capacity to make big decisions, such as where they live, but are often able to make day to day decisions such as what to wear or who to sit with.

The Mental Capacity Act (2005) says that a person should make their own decisions and where this is not possible because they lack the mental capacity to do so, that they should play as 'big a role as possible in decision-making processes that directly affect them.' (Social Care Institute of Excellence 2010).

A decision-making agreement is a way to know which decisions the person makes, and how to support them to do this. A few people at Bruce Lodge already have decision-making agreements, and Lisa is working to increase this number so that she is confident that they are supporting people to make as many decisions as possible.

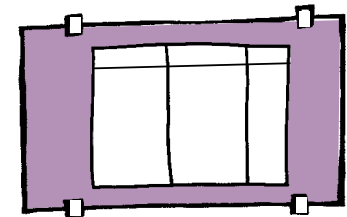
Here is Marie's.



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Marie's decision-making agreement

Decision	How Marie must be involved and who else can help with this decision	Who makes the final decision?
What time to get up	Marie will get up when she is ready	Marie
When Marie goes out	Listen to Marie about places she would like to visit and let her know in advance when she is going out with daily reminders	The home
Bath or shower	Ask Marie which she would prefer	Marie
What Marie eats	Offer Marie a choice of two meals	Marie
Choice of clothes	Show Marie a range of clothes from her wardrobe	Marie decides what colours and which clothes
How much money to spend from her allowance and what on	Talk with Marie about how much money she has spent each week and on what. Discuss options she may wish to spend the remainder on	Marie



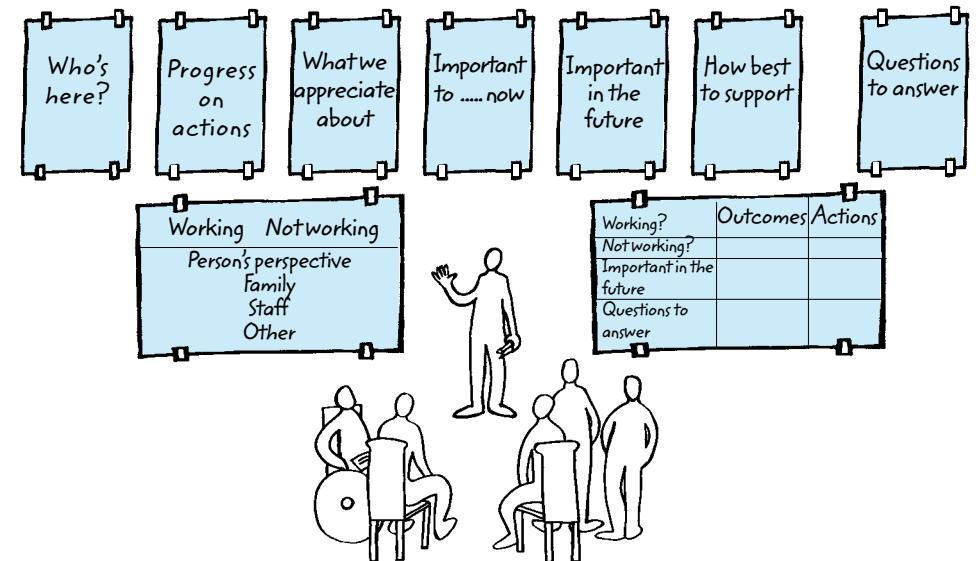
Person-centred reviews

A person-centred review is an informal meeting that looks at what is working and not working in the person's life. This happens from different perspectives – what is working and not working for the person, what is working and not working from the families' point of view, and what the staff think is working and not working. When the person with dementia cannot tell us directly, then the people who know the person best – family and staff, make their 'best guess', and step into the person's shoes to think about what is working and not working from the person's viewpoint. Person-centred reviews also provide enough information to start a one-page profile or update a profile that is already being used.

Hearing from everyone about what is working gives an opportunity to acknowledge and appreciate what is going well, which can so often be overlooked. Looking at what is not working, and understanding possible reasons for this, is the first step to agreeing actions to change what is not working and improve the person's life. In Bruce Lodge these meetings,

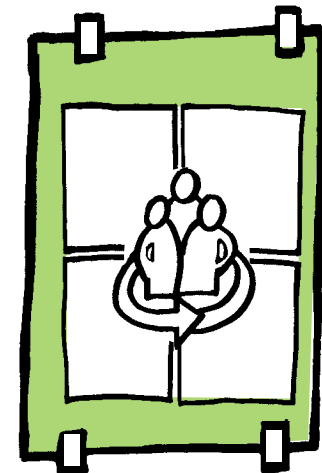
person-centred reviews, happen about every six months. The meetings are also a way to know how people want to use their individual time (we explain this in the next section), or to reflect on how this is going.

One of the terms associated with personalisation is 'co-production'. This means that people are involved in designing and influencing how their service is delivered. A person-centred review is an excellent example of co-production in practice, as this is where people say how they want their life and service to change (by looking at what is not working and changing this).



Individual time and matching staff

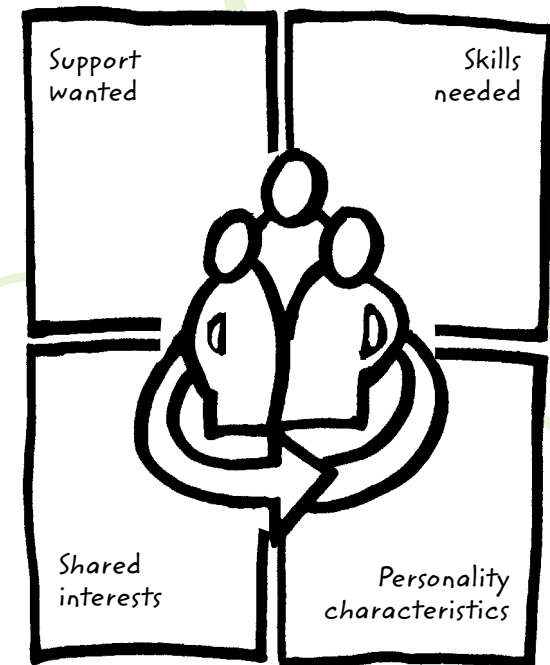
In truly personalised services, people choose how they use their time and who supports them. Lisa and her team introduced everyone having 2 hours of 'individual time' each month. Each person could choose what they wanted to do, when and where. They were matched to a staff member who shares their interests. This is how personal budgets can work in residential care homes. The Department of Health is piloting how to make this work in residential care homes as well. This means that instead of commissioners buying services, people will choose their service themselves, and naturally will want to know what they get for their money. The enquiries for places at Bruce Lodge have doubled since they have introduced each person having individual time.



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It is not just how people use their time, but who supports them, that really made a difference at Bruce Lodge. The quality of life of each person living with dementia is largely determined by their relationship with the people who support them. It is so important that people are supported by staff who know what matters to the person, understands how they communicate and make decisions and supports them in exactly the way they want to be supported. People may think that enhancing the quality of life for people with dementia is about amazing buildings and excellent hotel services but we think that the quality of relationships is even more important. The way we match staff and volunteers to people with dementia does not usually take into account the quality of relationships and shared interests. Lisa is starting to change that in Bruce Lodge.

As well as each person with dementia having a one-page profile, every member of staff and volunteer does as well, whether they are managers, night staff, admin staff or maintenance. Staff one-page profiles describe each staff member's hobbies and interests, and Lisa uses these to match staff to people who live at Bruce Lodge for their individual time.




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Staff one-page profile from Roy



Roy Boswell



What people like & admire about me

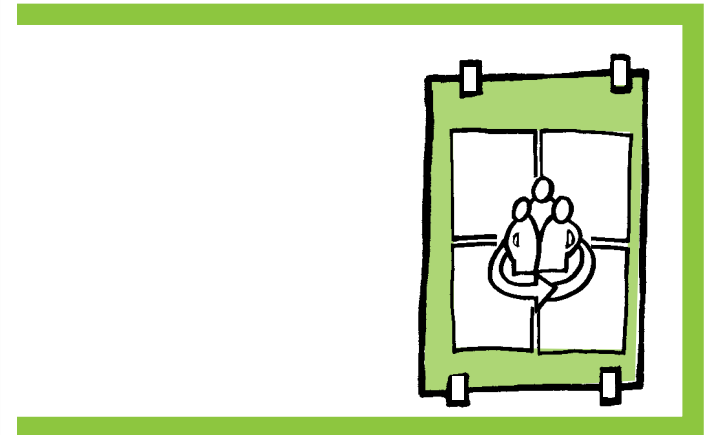
- Honesty
- Reliability
- Hard Working
- Caring
- Good sense of humour

What's important to me...

- My wife and family (always!).
- I love holidays in the Greek Islands, eating out, gardening and keeping active.
- I love going to watch Stockport County.
- Reading the daily papers, doing cross words and watching films on T.V.
- I love good music and having a laugh with my friends in the pub on Friday nights – I enjoy a lager.
- Being part of a team and also being self motivated.
- Like to learn and change to improve.
- Enjoying my job (which luckily I do!).
- Darts – Playing and watching.
- I enjoy eating out, especially curries.
- Enjoy the theatre, mainly musicals.
- I enjoy going to the cinema to watch Horrors.
- I enjoy walking anywhere – I don't drive.
- I love animals – like going to zoos.
- I enjoy swimming.
- I like horse racing.
- I quite enjoy shopping.

How best to support me...

- Give me respect
- Keep me informed, please don't ignore me
- Be honest with me, tell me the truth – good or bad
- Be positive around me, I hate negative attitudes
- Be reliable
- Give me knowledge to help me improve as I'm always willing to learn

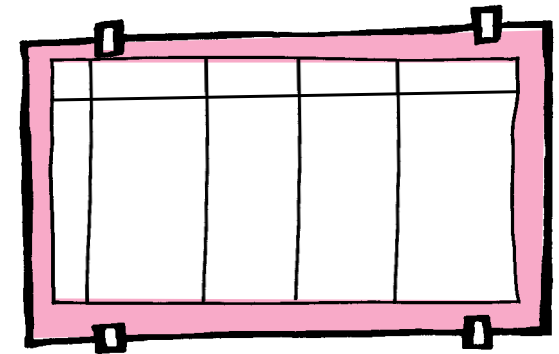


Learning logs

Every service requires the daily recording of what happened during the day. As staff work with people they are learning more about each person and how to support them well. It is vital that this important learning is recorded, shared and used. Learning logs are a way to do this. Learning logs are what we use to learn how to make changes to better support a person. At Bruce Lodge the staff use a learning log to record the person's individual time.

After four or five learning logs have been filled in about a person, the senior looks at the information and uses it to update the person's one-page profile, as there is likely to be learning about both what is important to the person, and how best to support them (and possibly appreciations too).

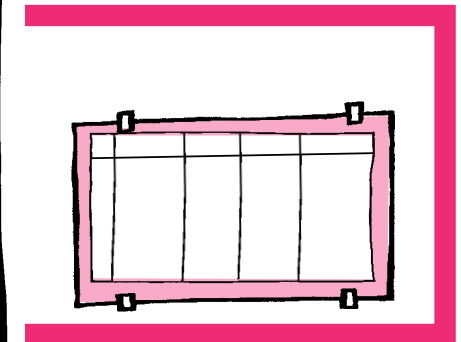
The learning log has 4 columns, as you can see from Winifred's example.



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Winifred's learning log

Date	What did the person do?	Who was there?	What did you learn about what worked well?	What did you learn about what didn't work?
7th June 2012	Getting up and ready to do the household chores with Beryl	Winifred and Beryl	Winifred was in her nightie and reluctant to get dressed. Beryl found leaving her be in her bedroom for five minutes, then taking a tea tray in and having a brew together worked. Then asking Winifred if she wants to get dressed and talking about the chores they need to get done encouraged Winifred and she eagerly got dressed ready make a start	Rushing Winifred; it needs to be at her pace
9th June 2012	Washing and drying the pots in the kitchenette	Winifred and Beryl	Winifred was singing as she washed up. Lots of hugs and cuddles. Telling Winifred often what a good job she is doing really motivates her and gives her joy. Winifred was happier to take a break if you walk arm in arm to sit down together	Winifred is reluctant to take a break and have a seat when cleaning
14th June 2012	Polishing all the handrails on the corridors	Winifred Beryl, Roy and Sandra	Taking a break with a small group. Having a morning break from her chores with Beryl Sandra and Roy	Working alone; need to keep bobbing back to Winifred to see how she is doing

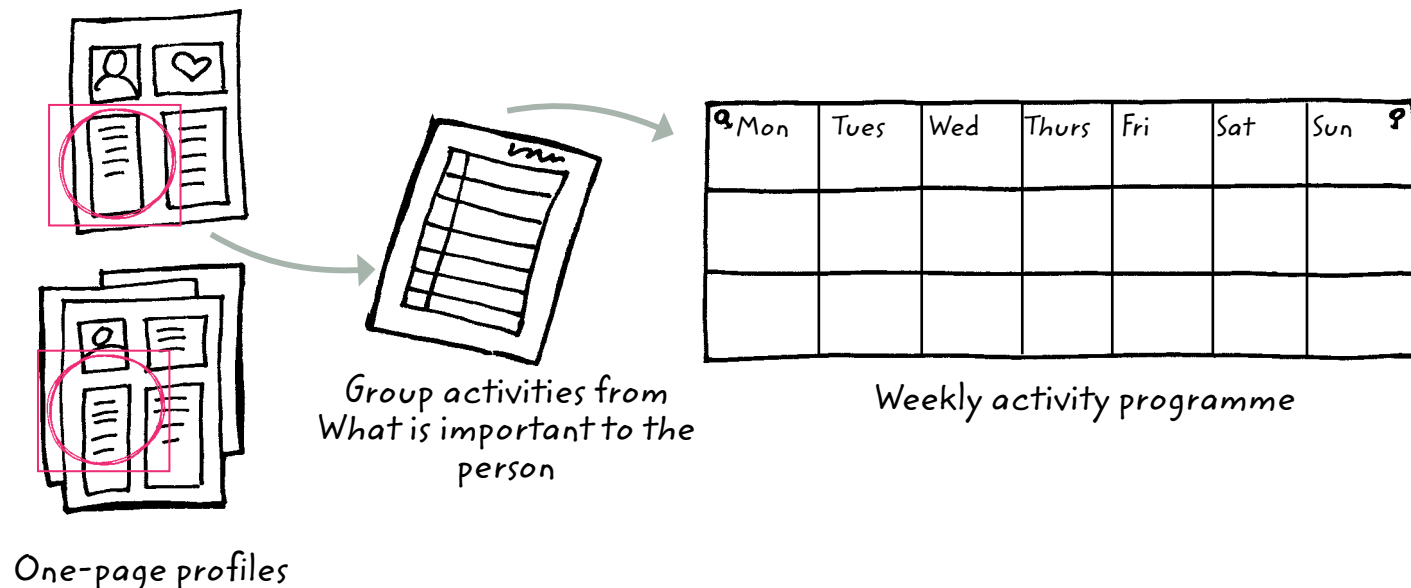


Developing a group activities programme from one-page profiles

It is brilliant to hear how choirs are being introduced to some residential care homes. Most care homes have an activity programme that includes a smattering of arts and crafts. Lisa and the leadership team at Bruce Lodge took a different approach to developing their group activities programme.

They looked at everyone's one-page profile, and at what was important to each person. They listed all the things from the one-page profiles that could be done in a group, and where

it was important to more than one person. This gave a list of potential activities that were important to people who live at Bruce Lodge, and ones that other people may be interested in trying too. There was no bingo or arts and crafts at all. One of the seniors, Joy, then developed this list into a weekly activity programme. Using this approach, people living with dementia at Bruce Lodge had an opportunity to do more of what is important to them, or try new activities that other people already enjoy.



One-page profiles and volunteers

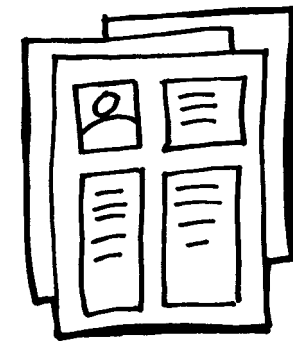
Sometimes people (usually people who work in other service sectors) are shocked that people living at Bruce Lodge only have two hours individual time a month. It is as much as is possible within the existing resources. There was no additional staff or funding to make this happen. However, we wanted to extend these hours, and needed to look beyond paid staff to do this. We also wanted to think about people being part of their community and extending the friends and relationships that people have.

To do this we are starting to work with dementia friends, volunteers, local businesses, faith communities, time-banks and Community Circles.

One example is supporting volunteers to have one-page profiles and matching them to an individual based on shared interests. This is different from the way it works with staff. When Lisa matches a person living at Bruce Lodge with a staff member, she starts with how the person wants to spend their individual time, and then looks at all the staff one-page

profiles to see who shares an interest. With volunteers, it is the other way round. You start with the interests that the volunteer has, and then look at the one-page profiles of the individuals, to see who may share the volunteers interests. Using this approach, volunteers are able to share their hobbies, interests, and passions with someone with dementia who shares one or more of these interests. This is a win-win situation, for the person, the volunteer and Bruce Lodge. Volunteers are more likely to stay and feel like they are contributing if they can share their hobbies and interests with someone. They immediately have something in common to start their relationship. It also makes it more likely that the volunteer can take the person to places where other people share the same interests; in the community, in informal groups or clubs.


As a volunteer's one-page profile also includes how they want to be supported, Lisa and her team can feel more confident in the way that they support each volunteer.



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Andy's volunteer one-page profile

Borough Care Andy's one page profile as a dementia friend



What people appreciate about me

Big foodie and great cook, goes the extra mile to help, patient, caring, conscientious, organised, positive attitude

What's important to me

- My family, Helen and my three daughters Ellie, Laura and Kate.
- Speaking to my brother every week, and texting a couple of times a week
- Good freshly ground coffee – every day
- Good wine – at the weekend
- Eating out - trying new restaurants when we can
- To be fit - cycling (weekend cycling with friends) and swimming each week
- Being organised and prepared
- Going to the cinema a couple of times a month (anything except rom-coms)
- Having barbecues in the garden when the weather is warm enough
- Learning Spanish (class on Monday evening)

If I could I would

- Go wine tasting
- Train as a barista
- Go power boating
- Go outdoor swimming
- Go canoeing in an Indian canoe (lake not sea)
- Explore Manchester more (art galleries etc)

How best to support me as a dementia friend

- I need to feel confident that I can support the person I am matched to, and have all the information I need
- To arrange in advance when I am going to visit, and have as much notice as possible if things change. I would hate to turn up and things have changed and not be told.
- Contacting me by my mobile is best.
- To know who to contact if there are any problems
- To be honest and direct with me if things are not working out



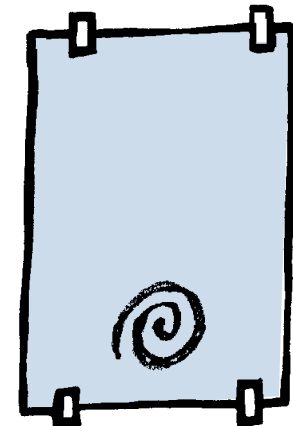
Working Together for Change

Earlier we mentioned how co-production means people being involved in designing and directing their service. One-page profiles and person-centred reviews are a way for people to influence their individual service, and Working Together for Change is a way for people living with dementia to influence strategic planning.

Working Together for Change is an 8 stage process that has been developed, tested and refined over the last five years and is used internationally, from schools to services for older people, to deliver inclusive strategic change. Lisa and the leadership team used Working Together for Change to plan further developments at Bruce Lodge. At the end of the person-centred review the person and their family were asked to identify:

- Top 2 things that were working for the person.
- Top 2 things that were not working for the person.
- Top 2 things that the person would like to have in the future.

Lisa and the leadership team then spent the day with an independent facilitator clustering, themeing and analysing this information. This told them the most significant things that were working for people living at Bruce Lodge, what people wanted to see in the future, and the key areas and priorities for change. This led to an 8 point action plan, which will lead to strategic changes for people living at Bruce Lodge. This is the only way we know of where the views of each person living with dementia can directly influence how a service develops.



Introduction	One-page profiles	Communication charts	Decision-making agreements	Person-centred reviews	Individual time and matching staff	Learning logs	Developing a group activities	One-page profiles and volunteers	Working Together for Change
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8 step process graphic



Introduction	One-page profiles	Communication charts	Decision-making agreements	Person-centred reviews	Individual time and matching staff	Learning logs	Developing a group activities	One-page profiles and volunteers	Working Together for Change
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What next?

These 9 person-centred practices are ways to build on person-centred care and deliver personalised services to people living with dementia. Personal budgets are the most powerful way to achieve personalisation, and there are signs that they will soon have an impact on residential care. Every care home or homecare provider can do something now to introduce person-centred practices, to develop your service in the direction of personalisation.

Lisa learned that apart from training (all of her staff had half a day training on one-page profiles and learning logs) and direct coaching and support. Introducing these 9 person-centred practices did not cost any more, but had a profound impact on people and staff.

Lisa used a free self-assessment, to see where she was starting from. The self-assessment is called Progress for Providers – care homes. You can download a free copy, or complete this online by going to progressforproviders.org.

If you want to know more about these person-centred practices, and learn about others (for example decision-making profiles, community maps, relationship circles, four plus one questions) you may be interested in this book: www.hsapress.co.uk/publications/books.aspx

To read about how this happened, stories and examples, we will send you a complimentary book, if you fill in this form with your email address and an address for us to post the book to.

About the authors



Dr Helen Sanderson

Helen Sanderson has led the development of person-centred thinking and planning in the UK over the last fifteen years. Helen was the Department of Health's expert advisor on person-centred approaches to the Valuing People Support and Putting People First Teams. She co-authored the first Department of Health Guidance on person-centred planning, and the 2010 guidance 'Personalisation through person-centred planning'. Helen has worked in health and social care for over 25 years.

Her PhD is on person-centred planning and organisational change and she has written over fifteen books on person-centred thinking, planning, community and personalisation.

Helen leads HSA, an award-winning international development agency passionate about how person-centred thinking and planning can create person-centred change and contribute to changing people's lives, organisations and communities. She is Director Emeritus of the International Learning Community for Person-Centred Practices.



Gill Bailey

Gill Bailey trained originally as a nurse and has worked with a range of providers and in commissioning across health and social care for over 25 years. In the last 10 years her work has focussed on supporting people living with dementia. She is a Dementia Care Mapper and has a diploma in Dementia Studies. Gill is a consultant with HSA and is currently working with providers to introduce Individual Service Funds in residential care, for people living with dementia.

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