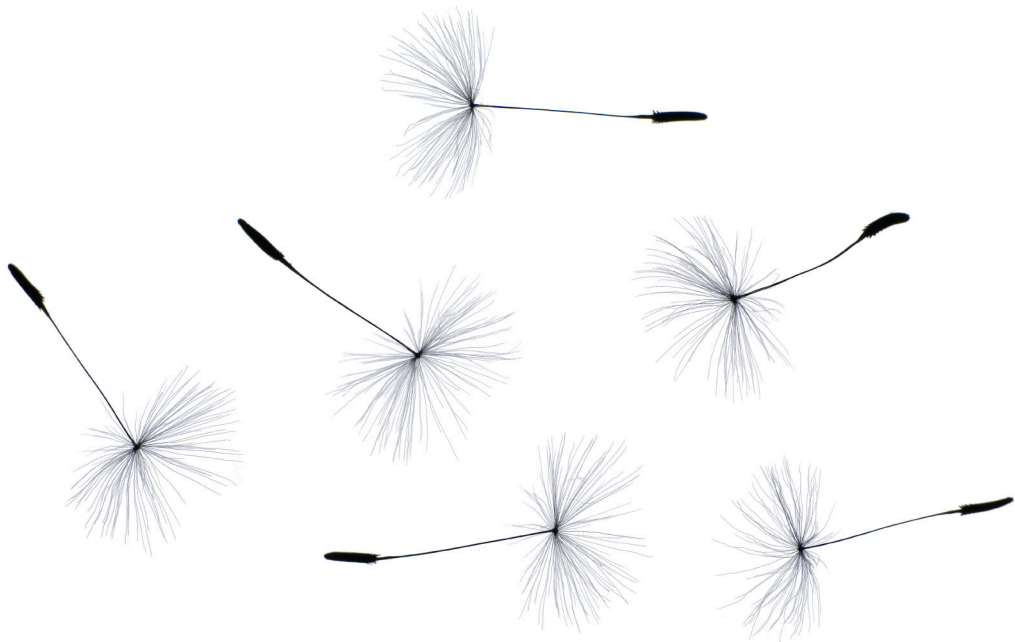


Living well

Using person centred thinking tools with people who have a life limiting illness



Madge's story

Madge's person centred review took place in September. Madge, Sally and Ian - two of her children, Barbara - her neighbour, Josie and Tracey - health professionals, attended the review which Gill facilitated.

Madge lives on the Fylde Coast. Often described as being full of fun and a great teller of stories, she is comfortable talking with anybody. She has three children; Sally and Ian live nearby with their partners Stephen and Jane. Sam is her other son who lives in Australia. Sally and Stephen have two children; Jess and Jon. Ian and Jane have Mark and Kim. Madge adores her grandchildren whose ages range from six to eleven years. Madge is 67 years old and was diagnosed with cancer of the oesophagus one year ago. She had major surgery 10 months ago. She is doing her best to remain cheerful and get as much enjoyment as she can with her family and friends.

Madge loves having a tea or a coffee with Sally who calls at Madge's house each day to hear about how the children are doing. Sally knows not to push Madge to talk about her health - she respects that if Madge says she is ok she doesn't want to talk about it. Another highlight for Madge is Ian and his family going to hers for tea on Saturday and Sunday. Also going down to the sea front with Sally, Ian and the children on a Sunday. They often go for Sunday lunch to Madge's favourite, the Blue Anchor.

Madge would never miss chatting with Sam in Australia on Skype each Saturday evening. Sally or Ian always dial through for her as Madge openly says she struggles with technology but it mustn't clash with X Factor! Family and friends are the greatest joy in Madge's life. Her sister, Ann calls most days. If the weather is fine they have a wander down to the village. Madge looks forward to calling into Betty's cafe for a coffee and catch up with Ann. If Madge is tired, Ann will push her in her wheelchair; although Madge is quite embarrassed about using it.

Madge will really push herself to get to the luncheon club on Wednesdays to see Jane and Jim. They are her oldest friends. Barbara, Stan and Ron are other old friends of Madge and her late husband Jim. They often call on a Sunday evening and all enjoy a night in playing cards - gin rummy is a favourite.

Madge is irritated when people tell her it will be ok; the stark truth is we know it won't be ok and it is not helpful to pretend. Madge is taking things in her stride. What really makes Madge smile are the great things happening in people's lives; she would not want people to avoid telling her the great things in their life because they feel awkward.

Madge knows that her friends and family are aware of her sensitivity around food, they know not to fuss when she is eating or not eating and mostly respect this though rows still occur occasionally if Madge feels they are watching her too closely. She hates it when she is cheered on through every mouthful or for clearing her plate - she is clear that she is aware of the need to eat and will do so when she can. She has told family and friends they make mealtimes a nightmare when they comment that she hasn't eaten much. Madge is clear it is for the medics to monitor her food and wants no comments from family and friends around how much or little she eats.

Madge does her best to stay out of hospital she really fears having to be admitted. If she does have to go in she always takes her yellow bed socks. She describes them as her comfort blanket.

Madge becomes anxious about hospital appointments and asks that people leave her be if she is quiet when they are due. She is clear that if she wants to talk about it she will do. She appreciates medical staff giving her clear simple information and will become upset if she is talked over as though she is not there. Madge is an intelligent, forthright woman but finds it difficult to be assertive when in the company of medical professionals. Sally, Ian or Jane and Jim run Madge to the hospital appointments. She prefers them to sort out between themselves and just let her know who is picking her up and when. They are always at least an hour early otherwise Madge's anxiety goes through the roof. The less conversation about appointments and tests the better as far as Madge is concerned. Sally is seen as the main contact, with Madge's consent, for the health practitioners.

Madge's Update from Person Centred Review which took place in September 2010

Barbara, Madge's neighbour arranged for someone from the Macmillan support service to come and talk with Madge and Barbara about the benefits Madge was entitled to. As a result it emerged that Madge wasn't claiming everything she was entitled to. She is now in a position to pay a cleaner. A family friend whose company Madge really enjoys is now cleaning for Madge 3 hours each week. This means Sally and Ian can spend more time with Madge when they visit without having to try and keep on top of household chores as well. This has made a huge difference to Madge as she had felt she was asking too much of Sally and Ian which made her feel very guilty, but she can now relax and chat with them.

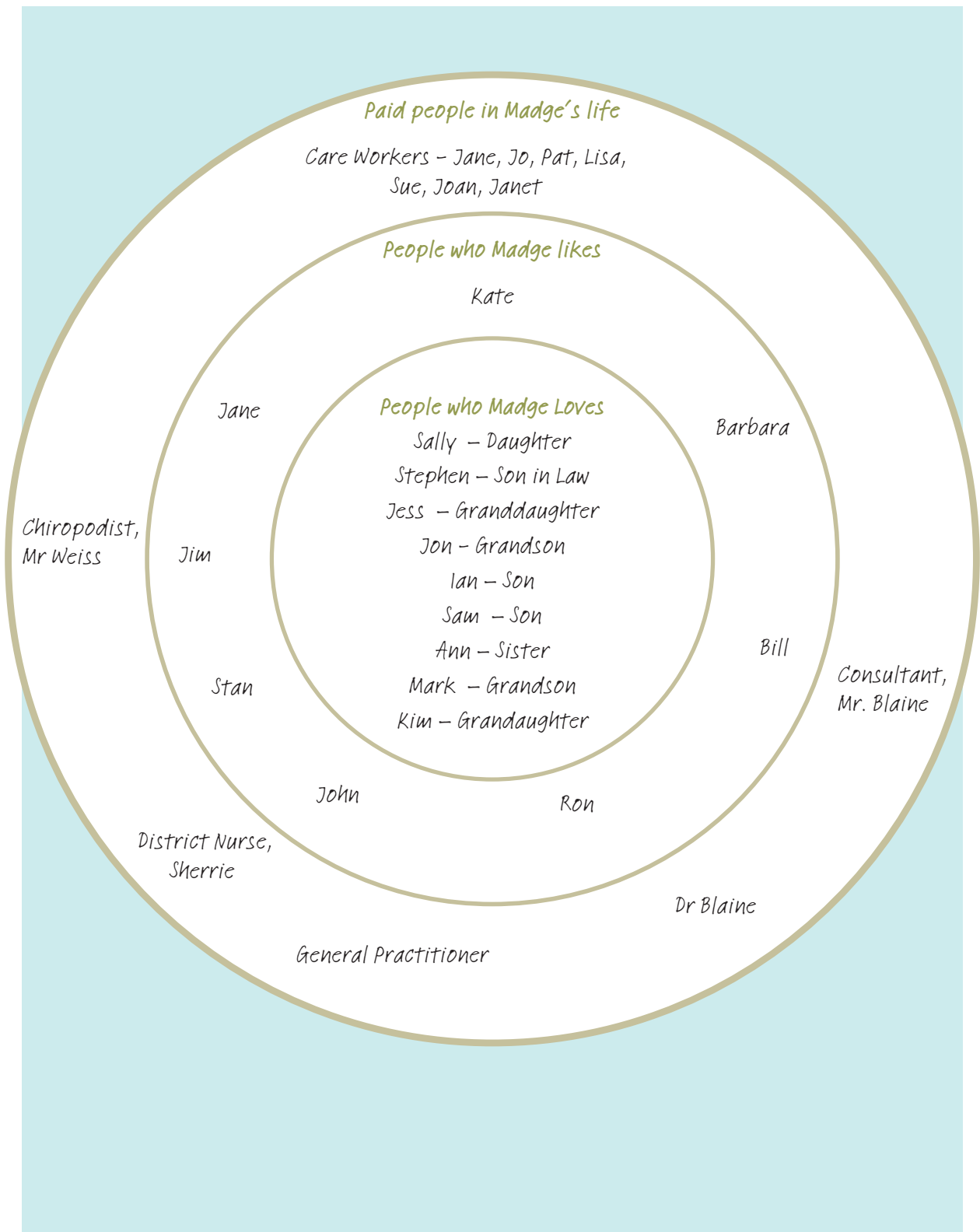
One of the things Madge really wanted to do when we explored the 'If I could I would' question was to have a mini break in London and go to see a show in the West End. Madge happily reports; "I had a ball Sally and I went to see The 39 Steps at The Criterion. It was wonderful". Another highlight was a cream tea at Harrods. "I had a cup of tea and a mousse, unusually for me I really enjoyed sitting down to eat with Sally, I never thought we would make this trip happen but by taking a step back and thinking this through at my person centred review we did it - fantastic."

Another difference made is that Sally, Madge's daughter spoke with her line manager at work and is now working reduced hours (3 days a week instead of 5). This has a huge impact on the opportunities for Sally and Madge to get out and do things together; it has also eased the pressure on Sally which in term delights Madge.

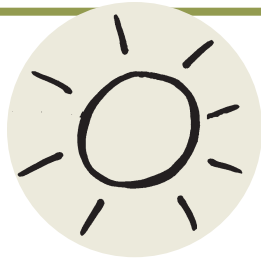
The dietician has visited Madge at home and taken her a number of options to increase her intake of nutrients - smooth soups, smooth cereals, enriched yoghurt drinks rather than the nutrient drinks which were delivered as a block.

10 November 2010

Thinking about relationships - Madge



What does a good day and a bad day look like for Madge?



Lots of family noise in the house.

Speaking to Sam.

Seeing or speaking on the phone with my grandchildren.

I get a picture my grandchildren have made at school.

The sun is shining!

I have a meal I enjoy – favourite foods fluctuate often.

I enjoy my cups of tea – at least 5 a day.

I go to sleep quickly and have a good night.

Enjoying peeled grapes – especially when lovingly peeled by any of my grandchildren.

I get outdoors and feel up to walking.

I spend an evening playing cards with friends or go to meet them at luncheon club or the tea dance, having fun with friends or just having good conversations. I love to talk.



I have a restless night.

I cannot face drinks or food.

Any day where I have a medical appointment especially endoscopies and having to wait for results.

I don't feel right and jump into panic mode that something is going badly wrong with me.

I do not see any of my family or friends.

Not having the energy to do the things I want to do – such as tidying the house.

Having to take my PRN medication due to discomfort – it makes me feel very groggy.

Having to have nutrient drinks because I cannot manage a meal.

I cannot face a cup of tea.

What is important to Madge, and how she wants to be supported

What Madge's family appreciate about her

Her unconditional love, her cuddles, she is always there for me, she goes the extra mile every day, I just love her – everything about her, her kindness.



What is important to Madge

- Sally, my daughter who comes to see me at my house after work each day, our coffee and chats together, hearing how the children are doing at school.*
- Ian, my son who comes for his tea Saturday and Sunday with my grandchildren whom I adore; Mark and Kim.*
- Staying healthy and out of hospital.*
- Sally and her husband Stephen taking me out to the seaside on a Sunday morning with Jess and Jon my beautiful grandchildren. Having our Sunday lunch out – the Blue Anchor is a favourite.*
- Speaking on Skype with Sam every Saturday.*
- That you share with me the great things that are happening in your life – I want to hear it, it cheers me.*
- My sister Ann popping in each day and having a walk into the village together – we sometimes go in Betty's cafe for coffee which is lovely.*
- Meeting up with Jane and Jim at the luncheon club Wednesdays.*
- Barbara, Stan and Ron coming round for an evening in and a game of cards – gin rummy is a favourite.*
- That I always take my yellow bed socks Sam bought me if I have to go in hospital for a stay – they are my comfort blanket.*
- I love grapes with the skin peeled off.*

How best to support Madge

Ask me how I am if I say I am ok, respect I do not want an in depth conversation, I will talk about my health when I need or want to, please do not push me on it.

Know that when I have examinations or treatment it is so irritating if you don't tell me what you are going to do with me before you try and do it.

Don't tell me it will all come out in the wash, we know it won't. I want no elephants in the room, lets just make the most of the time we have, and be as 'normal' as we can.

Give me clear and simple information. Do not talk over me as though I am not there; I am an intelligent woman. Give any detail to Sally she will remember better than me. It works best for me if any correspondence about my condition comes to me through Sally.

Know that I am aware of the need to eat and will do so when I can, do not make mealtimes a nightmare by watching my every mouthful or commenting if I don't eat much.

Do not make a fuss and cheer me on if I clear my plate. I want this focus on what I eat to stop – the medics will monitor this not family and friends.

Know that I cannot work Skype to speak with Sam on my own. I need Sally or Ian to set it up for me.

Know that I detest the hospital appointments and will be very quiet on the days they are due, leave me be I will talk if I want to.

Know that I use a wheelchair to get around if I am not up to walking but it embarrasses me terribly.

Work out between you who is coming with me to each appointment, then just let me know who is calling for me.

Know that I detest being late and get anxious – the earlier the better for me I must never be late!

What is working and not working in my life and what do I want to change?



Madge

Seeing lots of Sally, Ian and their families.

Having Sunday lunch at the Blue Anchor with Sally and the family, the noisy busy atmosphere works so well for Madge.

Going to luncheon club and the tea dance with friends.

Having evenings in with old friends playing cards, watching TV.

Speaking with Sam on Skype.

Having a big screen TV is wonderful.

Busy weekends with family and friends.,

Eating peeled grapes, drinking tea and coffee.

Family and friends sorting out her hospital appointments and taking her to them.

Dr. Prakesh, Madge's GP

Sal community nurse calling every few weeks.

More frequent off days, having to spend more and more time in bed.

Having to use her wheelchair when she feels jittery.

Not getting outdoors as often as she would like.

Not being able to look after the garden.

Too many telephone calls from friends.

Too many hospital appointments and having to continually repeat the same information to different people.

The long waits in the waiting area for some of her appointments.

Seeing Sally so tired out as she is doing so much for her.

The struggle to find food she can enjoy.

Mealtimes are uncomfortable; Madge feels she is being watched by everybody.

Weight loss. Madge has lost 3 stones in the last 5 months.

Looking gaunt.

Nutrient drinks.

Hospital admissions due to severe abdominal pain.

Not being able to go on holiday

PRN meds making Madge groggy.

Seeing how unhappy her family are and not being able to tell them everything is ok.

Not sleeping.

Not seeing John and Kate her old friends.

What is working and not working in my life and what do I want to change?



Family

Mum's wonderful attitude, character and determination to do as many things as she can.

Spending time with mum and chatting at her house each morning.

The children's love of their grandma and seeing them all enjoy time together.

Support from Ian and mum's friends.

Liaising with the health professionals on mum's behalf.

Support from Dr. Prakesh.

- More frequent off days, having to
- Mum insisting on doing things even when she is tired out such as tea dance and luncheon club.
- Sally never has time to do tasks at home or spend enough time with her partner and the children due to her employment and looking after mum.
- Eating with mum – it's become like there is an elephant in the room every time we eat together.
- Mum looking so gaunt.
- Looking after mum's house – cleaning, laundry, ironing and the like.
- Mum's weight loss, seeing her sadness when she thinks no-one is looking at her.
- Sam being in Australia.
- Mum not sleeping.

Staff

Support from Dr. Prakesh.

Support from Madge's family.

- Madge's weight loss, tiredness.
- Lack of sleep.
- Nutrient Drinks
- Madge's increase in hospital admissions.
- Lack of support for the family.

How I communicate with you - Madge

At this time	When I do this	It means	You should
Anytime.	Lie on the settee with my eyes closed.	I have a bad head or just feel off.	Leave me be I just need some quiet time.
Anytime.	I say I am going to have a shut eye.	I am tired and want you to go but please don't be offended.	Understand I simply need a rest to recharge my batteries and we can catch up another time, I will usually give you a call the following day.
When I am going out.	Ask shall I take my wheelchair.	I am feeling a bit jittery.	Help me into my chair or put it in the car.
At mealtimes.	Play with my food.	I don't want it.	Do not pass comment or offer me a hundred other things just leave it.

If I could, I would...Madge

I would go on holiday in a log cabin by the Lake in Windermere.

I would visit Sam in Australia.

I would go to a show in London.

Go on a cruise with the children and grandchildren.

What I want and do not want in the future - hopes and fears



That I will have a long period of remission.

To keep as well as I can for as long as I can.

To keep going to the market each week.

To stay out of hospital.

Spend time with my friends at the luncheon club.

Continue going to the tea dance at the Trafford Centre with Jane and Jim each month.

To go away on holiday by the sea, a little cottage in Wales would be lovely with Ian, Sally and the grandchildren.

That I will die quickly and not put my family through a long drawn out end.



Being in pain.

Being housebound or even worse bed bound.

Having to be admitted to hospital.

Not seeing Sam again.

That I make my children unhappy.

That I lose the health I have and have a long drawn out death.

That I become incontinent – this terrifies me.

If I looked so gaunt it would pain my family and friends to look at me.

Making changes to my life - Madge's action plan

Who	What	By when
Sally	Will speak to Dr. Prakesh about Madge's PRN meds.	8th September 2010
Ian	Will arrange a weekend break for Sally and Madge in London taking in a trip to a show in the West End.	15th September 2010
Ian and Jane	Have Sally's children stay over with them when Sally and Madge go away.	On the weekend they go away
Sally	Will speak to her husband, Stephen, about working away less for a while.	6th September 2010
Barbara, Madge's neighbour	Will make enquiries to look at what benefits, such as attendance allowance, Madge is entitled to - with a view to paying a cleaner.	15th September 2010
Madge and Ian	Will contact the bank to look at her financial situation to see if she can afford a cleaner for herself and Sally.	15th September 2010
Ian	Will speak with Sam to work out if he can visit and stay with Ian for a few weeks.	8th September 2010
Sally	Will contact John and Kate (Madge's old friends in London) to arrange to visit with Ian and mum and go to see a show in the West End.	28th September 2010
Tracey (community nurse)	Will contact the consultant Mr. John and the social worker to arrange a meeting about Madge's deteriorating health and options for additional support for the family, options to the nutritional drinks and insomnia.	8th September
Sally and Ian	Will look at what resources are out there to support Madge to get out more.	30th September 2010
Sally	Will arrange a meeting with her supervisor to take a period of leave from her post.	8th September 2010

What do I want to add as I think about the end of my life?

	What I want	What I don't want	My family's view
Where I want to die	At home.	To be in hospital on my own.	Sally Ian and Sam want to be with me.
About my funeral (music, readings, flowers etc)	I would like my funeral to be quick with just the 2 hymns and one reading - at the crem. at Carlton. No flowers - a donation to charity of people's own choice if they wish. Donation made by them - I don't want Sally to have anything to worry about.	Black clothes.	My family are happy with this.
About being buried or cremated (clothes, hair, jewellery)	I want to be cremated Sally and I have chosen the clothes I will wear, I want my glasses on.	A shroud!	I would want to lie in rest at the funeral directors, not at home.
About the scattering of my ashes	Sally Ian and Sam scatter my ashes together at the end of Blackpool pier into the sea. At least if I go suddenly and Sam does not get back in time from Australia the three of them can do this together which matters so much to me.	My ashes standing about in a pot!	The children have promised me they will do this together.
About what people do after my funeral (food, drink, a celebration, memorial)	My family and friends to go back to Sally's with a buffet I have ordered from Marks and Spencer's and remember with happiness the time we spent together.		The family will do what Madge wants.
About a gravestone or marker for my ashes or burial place	I just want those who love me to carry me in their heart, they will always feel close to me if they are by the sea - any sea - I just love the sea!	A physical memorial.	Sally would like a grave to visit but accepts my wishes. We have agreed to have a bench on Abbey Hill where the sea runs by but no plaque, she can go and sit there and think of me.
What else is important to me?	Sally and Ian know the things they can give to charity and who I want to have of my remaining possessions.	Only Sally to sort my stuff out.	My family have agreed to this.

How would I like to be remembered? Madge

Do not dwell on my frailty when you think of me remember the fun and laughter we shared.

Madge would like her three children to meet on Blackpool pier and scatter her ashes in the sea together.

Go to the illuminations some years and walk along the front and talk about the wonderful times we knew.

End of life decision making agreement - Madge

Decisions to be made	How is Madge involved and who else is involved	How the decision is made and who makes the final decision
Around my treatments and my condition.	I want to be fully involved but it makes more sense if information comes to me through Sally. She knows how to put things across to me and helps me come to decisions, I cannot follow some of the consultants.	Madge.
Where I will be looked after if I become very dependant?	I want Sally and Ian to be OK. I would want to stay at home but know they will do what is best if it gets to the point they find it too difficult.	Sally and Ian.
Where to die.	Madge talks through with her son Ian and daughter Sally.	Madge – her preferred place for her end of life is at home but she is comfortable for Sally and Ian to ultimately control this decision given that she trusts them completely.
How she wants to be remembered.	Madge, Sally and Ian (daughter and son) will discuss. Madge will also talk to Sam her other son who lives in Australia. Alison from the long term condition team also has some ideas for Madge.	Madge.
Whether to be resuscitated.	Madge, the district nurse, her consultant and his medical team.	Madge has decided she does not want to be. Her decision to be respected by medical team.
Which funeral directors.	Madge, Sally and Ian.	Madge.

Pat's story

My Mum, Pat, has been living with the long term condition C.O.P.D. (chronic obstructive pulmonary disease) for several years now. The disease has left Mum requiring oxygen for 24 hours of the day. She is unable to walk more than a few steps and dependent upon family for personal care and household tasks. Mum will tell you how much she hates not being able to do things for herself as she has been busy throughout her life, often juggling several part time jobs at once. She particularly misses ironing and says, "I used to love ironing, but now I don't have the strength to lift the iron!"

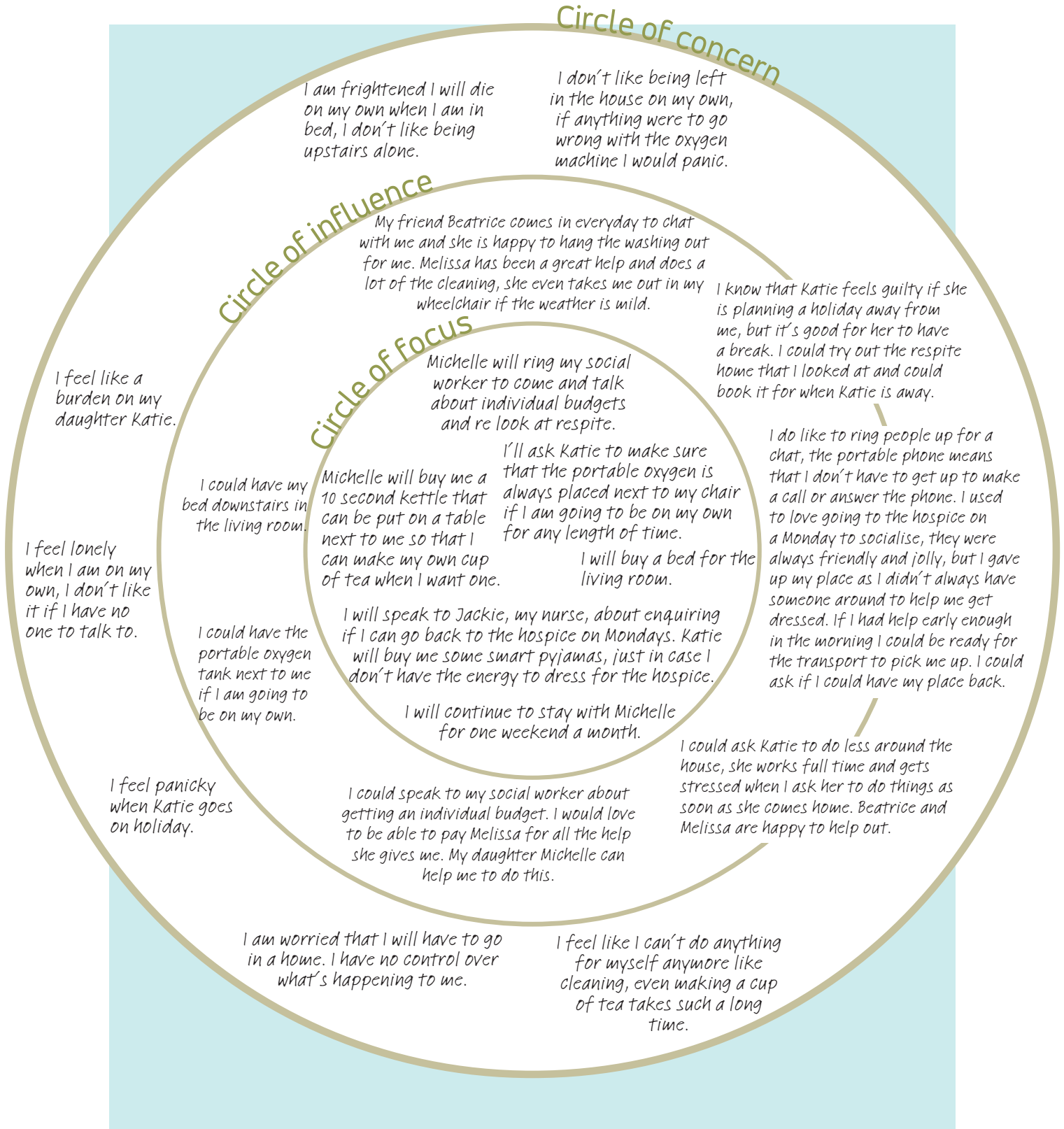
My step dad, John had been Mum's main carer, although he too had been fighting cancer for years. When he passed away suddenly, Mum's world changed dramatically. Not only was she trying to come to terms with the death of her husband but was also worrying about what the future held for her. She felt overwhelmed by her situation and was having to rely on my sister Katie, who still lives at home and works as a full time nurse, for all the support she needed.

As the weeks passed after my step dad's death, I could see the strain that both my Mum and sister were under and wanted to help out. It would have felt easy to make some suggestions to my Mum and sister about the types of supports and services that are available but I wanted to make sure that my Mum felt that anything that happened was what she wanted, as opposed to what I assumed she needed. I had tried to organise support from social services in the past and that had failed miserably, leaving her mistrustful of the world of services.

I used the 'circle of influence' tool to identify all of the things that were contributing to Mum feeling anxious and stressed and recorded these. We then explored what Mum could do about addressing these concerns and turn the ideas into practical actions.

The tool was helpful on several levels and by giving my Mum time to talk things through, I learned so much more about what was important to and for her. It's so easy to make assumptions when you know someone really well. Mum was able to explore her feeling and, most importantly, make decisions about what needed to happen to address her concerns. Using this tool has helped her to regain some control over her life and the following day she contacted her social worker to organise a direct payment and decided who she wanted to employ as her personal assistant.

Circle of influence - Pat



What is important to Pat, and how she wants to be supported

What those who know Pat best say they like and admire about her

- Funny, loving, generous to a fault, good friend and neighbour, compassionate, great company, town and country planner, thoughtful, endearing, interested in others, always wants to help, ability to laugh at herself.



What is important to Pat

- To have people around her to chat with every day. Pat loves company and always has a warm welcome for visitors who pop in most days.
- To stay living in her own home in the street where everyone knows her.
- To have new books to read every week, usually 5 or 6 which are delivered to the door by the mobile library.
- That the house and garden are kept tidy.
- To always know how much money she has in her bank account.
- To know that her son's grave is tidy, cared for and has flowers on it once every 4 to 6 weeks and to visit it in good weather when feeling well enough.
- Pat must have a 99 cornet with a flake, raspberry sauce and sprinkles from the ice cream van every day, unless out and about.
- To feel fully involved in all aspects of her children, grandchildren and great grandchild's lives. Preferably in person, but also via Facebook.
- In particular, to see or hear from her children Michelle and Carl 3 or 4 times a week and to see or speak to Katie every day and to know everyone is safe and well.
- To enjoy a cup of tea and a chat with her friend and neighbour Beatrice most days.
- To see her great grandson Oliver at least once a week.
- To be able to chat to people on the phone most days and to catch up with her sister, Sheila at least once a week.
- To see Jodi and her daughter Danielle most days and to go out shopping or for meals with them whenever she feels well enough.

How best to support Pat

Pat is still grieving for her husband who passed away earlier this year. She needs to know that it's ok to take the time to reminisce and talk about her loss.

Pat hates to be alone and feels anxious if this is necessary. Ensure that the front door is left unlocked during the day so that friends and neighbours can pop in at any time. Make sure that the phone is within reach as Pat will try to find it when it is ringing and this can result in her becoming breathless and panicky.

Pat has C.O.P.D. (Chronic obstructive pulmonary disease) and emphysema and uses an oxygen machine 24 hours a day to help her to breath. Check that she has her portable oxygen cylinder nearby (with spare batteries) in case there is a power cut or a problem with the machine. And that her medication and nebulizer are within arms reach.

Pat can become frustrated by her inability to do all the things she used to, such as ironing, household chores and popping out to the shops. She hates having to rely on others to do so much for her and feels like a burden. Reassure her that what she is asking for is not a problem and try to spot what needs doing before she has to ask.

Pat loves going to the local hospice day centre on Mondays. She needs to have plenty of time to get ready in the morning and will feel stressed and breathless if she is rushed.

Pat is susceptible to severe chest infections, never visit her if you are unwell.