



Madge's story

Person centred
thinking and
end of life

Madge's story

Madge, 67, lives on the Fylde Coast. She is full of fun, a great story teller and is comfortable talking with anybody. She has three children: Sally and Ian live nearby with their partners Stephen and Jane. Both couples have two children each. Sam is her other son who lives in Australia. Madge adores her grandchildren whose ages range from six to eleven years. Madge was diagnosed with cancer of the oesophagus one year ago and 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. The people in Madge's life are so vitally important to her and we developed a **relationship circle** which helped really explore who were the people Madge simply enjoyed spending time with, who helped with which decisions and who were Madge's natural supports - a great way to frame our conversation and learn so much about the people and activities which really matter to Madge.

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 her place for tea on Saturday and Sunday and 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 restaurant, 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. This 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. 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 about 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. We explored further her **hopes and fears** which added a dimension

to our conversations around what **she wanted and didn't want in the future**, this happened very naturally as we framed our conversations around the tool.

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 and I developed a **communication chart** which was really useful in helping Madge's family, friends and professionals in her life to respond to her in ways which supported her well

Madge had a person centred review which helped her think well with her family, a couple of her friends and the health professionals who supported her, about the things which were **working and not working** from various perspectives. This helped create an **action plan** which would improve matters for Madge and those around her.

Based on the information we had captured over previous weeks whilst using 'Living Well... thinking and planning for the end of your life', we further developed Madge's **one page profile** which she would share with her family, friends and health professionals.

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. Sally asked why her mum hadn't said earlier and began organising it following a discussion with the Macmillan nurse the following day.

Madge loved going to London and happily reported; "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 - it was fantastic."

Madge and Sally used the **good day bad day** exercise a couple of weeks later, which added further detail to Madge's one page profile. They also explored Madge's **hopes and fears** about the future. They drilled down around this by thinking what a good hospital appointment looked like and what a really bad one looked like. We then worked from that to develop a specific one page summary around what those accompanying Madge to the appointments and the consultants and nursing staff needed to know and do, to successfully support Madge - even knowing that you should always take a pack of extra strong Trebor mints for Madge to suck whilst having her chemo, as she hated the taste the treatment gave in her mouth. Madge was able to address a number of her fears by developing best support sheets around a number of situations to avoid her worst fears happening.

Barbara, Madge's neighbour, arranged for someone from the Macmillan support service to come and talk with them about the benefits she was entitled to and as a result, found she wasn't claiming everything she was entitled to. This means she is now in

a position to pay a cleaner, so a family friend whose company Madge really enjoys is now cleaning for three 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.

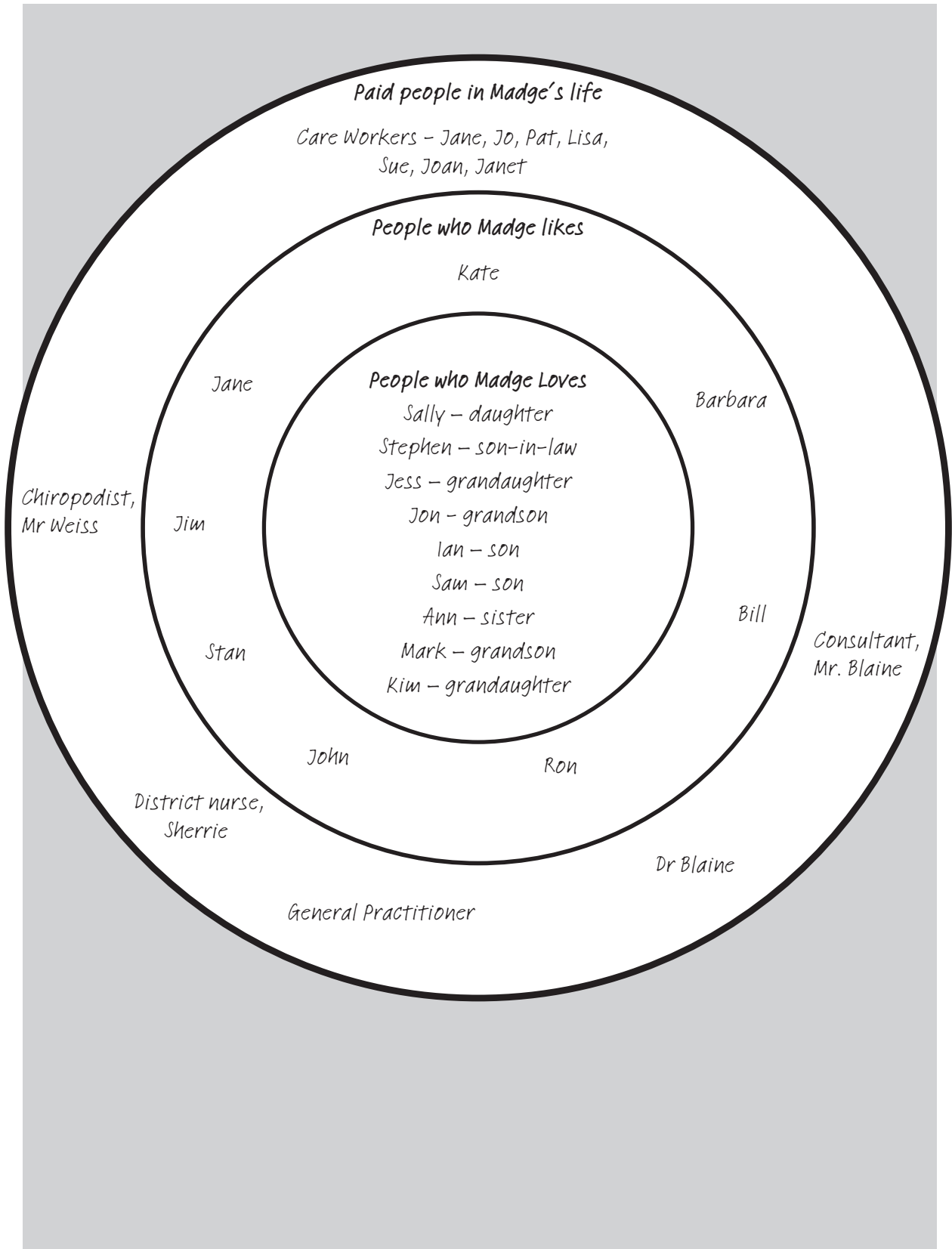
Another difference is that Sally spoke with her line manager at work and is now working reduced hours (three days a week instead of five). This has a huge impact on the opportunities for Sally and Madge to get out and do things together. It has also eased the pressure on Sally which in turn delights 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 and enriched yoghurt drinks, rather than the nutrient drinks which were delivered as a block.



As time passed, the family started to think together with Madge, about what she wanted to add to the information they had captured via some of the person centred thinking tools in 'Living Well' and they began to explore the **thinking and planning for the end of your life** section of 'Living Well'. Madge was very clear about how she wanted to be remembered and was confident Sally, Ian and Sam would ensure her wishes would be followed. They added to the **what I want and don't want in the future as I think about the end of my life** and developed a **decision making agreement** more specific to end of life. It was also at this point, by thinking back over

previous conversations and information Madge had gathered that she talked through with Sally, the arrangements she wanted in place prior to and at the end of life, including funeral arrangements afterwards.

Thinking about relationships - Madge



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

Hopes	Fears
	
<p><i>That I will have a long period of remission.</i></p> <p><i>To keep as well as I can, for as long as I can.</i></p> <p><i>To keep going to the market each week.</i></p> <p><i>To stay out of hospital.</i></p> <p><i>Spend time with my friends at the luncheon club.</i></p> <p><i>Continue going to the tea dance at the Trafford Centre with Jane and Jim each month.</i></p> <p><i>To go away on holiday by the sea. A little cottage in Wales would be lovely with Ian, Sally and the grandchildren.</i></p> <p><i>That I will die quickly and not put my family through a long drawn out end.</i></p>	<p><i>Being in pain.</i></p> <p><i>Being housebound or even worse bed bound.</i></p> <p><i>Having to be admitted to hospital.</i></p> <p><i>Not seeing Sam again.</i></p> <p><i>That I make my children unhappy.</i></p> <p><i>That I lose the health I have and have a long drawn out death.</i></p> <p><i>That I become incontinent – this terrifies me.</i></p> <p><i>If I looked so gaunt it would pain my family and friends to look at me.</i></p>

How I communicate with you - Madge

At this time	When I do this	It means	You should
<i>Anytime.</i>	<i>Lie on the settee with my eyes closed.</i>	<i>I have a bad head or just feel off.</i>	<i>Leave me be. I just need some quiet time.</i>
<i>Anytime.</i>	<i>I say I am going to have a shut eye.</i>	<i>I am tired and want you to go but please don't be offended.</i>	<i>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.</i>
<i>When I am going out.</i>	<i>Ask shall I take my wheelchair.</i>	<i>I am feeling a bit jittery.</i>	<i>Help me into my chair or put it in the car.</i>
<i>At mealtimes.</i>	<i>Play with my food.</i>	<i>I don't want it.</i>	<i>Do not pass comment or offer me a hundred other things - just leave it.</i>

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, the 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.

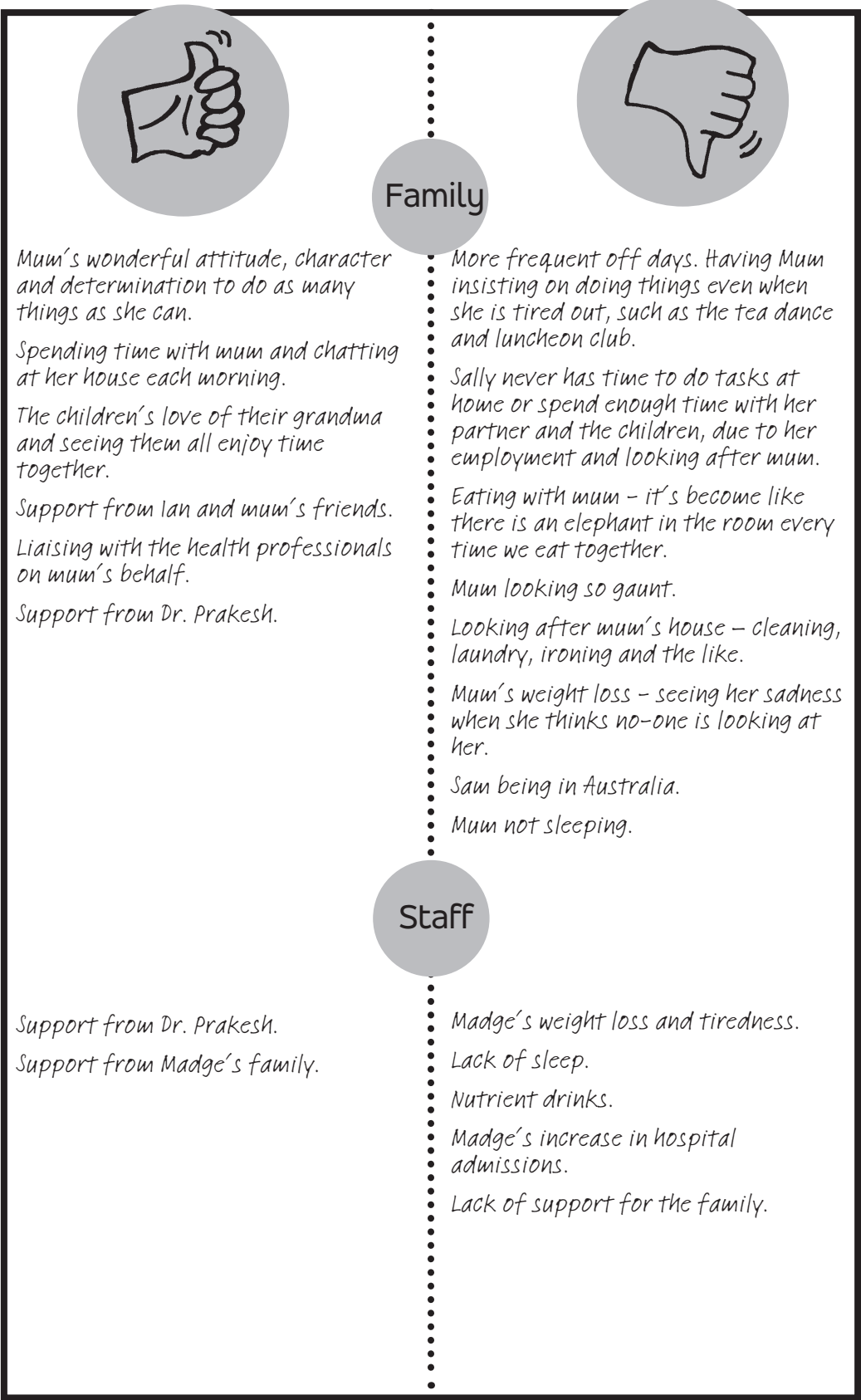
PRN meds making Madge groggy.

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?



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 to 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 2010
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 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 on 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 my 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 to Betty's cafe for coffee which is lovely.
- Meeting up with Jane and Jim at the luncheon club on 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 into 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 and 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. Let's 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!

If I could, I would...Madge

Go on holiday in a log cabin by the Lake in Windermere.

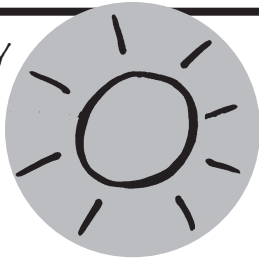
Visit Sam in Australia.

Go to a show in London.

Go on a cruise with the children and grandchildren.

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

Good day



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.

Bad day



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 meds 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 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 two hymns and one reading - at the crem., at Carlton. No flowers - a donation to a 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 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 had.

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
<i>Around my treatments and my condition.</i>	<i>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.</i>	<i>Madge.</i>
<i>Where I will be looked after if I become very dependant?</i>	<i>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 where they find it too difficult.</i>	<i>Sally and Ian.</i>
<i>Where to die.</i>	<i>Madge talks through with her son Ian and daughter Sally.</i>	<i>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.</i>
<i>How she wants to be remembered.</i>	<i>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.</i>	<i>Madge.</i>
<i>Whether to be resuscitated.</i>	<i>Madge, the district nurse, her consultant and his medical team.</i>	<i>Madge has decided she does not want to be. Her decision is to be respected by medical team.</i>
<i>Which funeral directors.</i>	<i>Madge, Sally and Ian.</i>	<i>Madge.</i>