



Introduction – Jo and Jess

Jess is 37 and has a learning disability that was first noticed by her parents in her childhood. Jess currently lives on her own in a housing association property where MacIntyre provide regular support classed as independent living with care. Jess lives about 40 minutes from her mum, Jo. Jess has a brother, aged 42, and regular contact with her dad, who lives fairly close to Jess.

Jo was interviewed for this case study.

What we have done

Listened to Jo

Creating this case study has been primarily about listening to Jo's experiences. She has been very candid and honest about how her family have approached the topic of death and dying over many years.

Jo: "People have said to me: How can you talk to Jess about death and dying?"

Jo's reply: "Because it's going to happen."

Supported Jess as her dad's health has deteriorated

Jess has been really worried about her dad, whose health has deteriorated. As a result of this deterioration, Jess has stopped going to stay with her dad. Jo has been constantly communicating with Jess' support team, and she's found using a communication book has been really helpful in enabling staff to know more about what is happening in their family. The communication book has helped Jo to highlight when Jess has been particularly stressed about her dad and flag up with staff that Jess will need extra support.

Supported Jo in arranging Jess' house move

Jess has decided to move from being close to her dad - who she is scared will die - to being nearer Jo, her brother and his wife. This is a big decision for Jess, who has lived in her current accommodation for many years. Another MacIntyre team will support Jess when she moves.



Jo explains:

“There’s been great communication from the team that will be taking over Jess’ support. For me, being able to pick up the phone on a bad day and know that someone in the team will be able to help/support is so important. There is always someone there, and having that point of contact is invaluable.”

Held ‘Let’s get together’ families meeting about end of life care

Jo joined the monthly MacIntyre ‘Let’s get together’ families meeting in December 2021, when host Nicola Payne (MacIntyre’s Family Consultant) was joined by one of MacIntyre’s Dying to Talk Project consultants, Beth Britton, to discuss the [Dying to Talk Project](#) and what support families need to have conversations about end of life care. The meeting produced rich and informative discussions that everyone contributed to. We realised that rather than families finding this a difficult topic to discuss, they actually wanted to talk about it and the meeting overran.

What did we learn?

Open communication (and humour) about death and dying has been helpful for Jo and Jess

Jo says that she and her family have always been very open with Jess:

“Jess knows Mum and dad won’t be around forever, and is fully aware of what happens and that she is going to die one day too.”

Jo says that humour has been helpful in making these conversations as easy as possible. Jess has had questions, and Jo has always answered these as best she could, never ignoring them or seeking to distract Jess. Questions have included Jess asking: ‘Why has/did this happen?’ when someone in her family has been very ill or has died. Jo has also tried to prepare Jess for the unexpected.

As Jo says:

“We don’t know what is round the corner.”



Jess has found her own ways to cope with bereavements

Jess has experienced three grandparents dying, the most recent being her maternal granddad in 2021. His death was very difficult for Jess, as she couldn't see him for a long time because of COVID-19. Jess managed to visit him three weeks before he died, and when he died Jo made sure she told Jess face-to-face not over the phone. Jess is learning to live with her bereavement, but cries a lot and texts 'I miss granddad' messages to her mum. Jo always talks through Jess' feeling with her.

Creative activity has been comforting for Jess

Jo has encouraged and supported Jess to express her grief creatively. Jess writes poems about people in her life who mean a lot to her and/or who have died. These are often celebratory or humorous. She always finishes with 'I miss you' (and cries).

How important it is for people supported to have access to individuals that they care about

Jess has recently been in hospital for a foot problem.

Jo says:

"It hit me while I was supporting Jess in hospital that if I hadn't been able to be with her how different the experience would have been for her, and even more so for a person who was very ill. COVID-19 has kept so many families apart, but it's important that health and care providers know how vital these support networks are for people who are vulnerable or disabled."

What are we pleased about?

Jo has been able to plan her funeral with Jess

Jo has talked about her funeral plans with Jess. They've discussed Jo's wishes for a celebration of her life, what music she would like, and for everyone to go to the pub afterwards for a drink. Jo feels that it's important that Jess knows her wishes and feels part of the planning process.



There is a plan in place for Jess after her parents have died

For Jo, having this plan in place is an important aspect of preparing for the future. In practical terms it means that Jess' brother will help Jess, along with his wife, and a cousin of Jess' who is a financial adviser will help too.

Jo says:

"The worry of what happens when you've gone is very real. For me, it's about being organised myself, knowing I've put in place everything I can. That gives me some peace of mind."

Jess has made some plans for her own death

Jo says:

"Many years ago when we knew about the extent of Jess' disabilities but realised she had mental capacity, we searched for a solicitor for Jess to talk to about making a will and doing her Power of Attorney. We eventually found a fantastic solicitor who was brilliant with Jess. Jess went on to make a will with the solicitor on her own and chose her attorneys for herself. We are very lucky that Jess has mental capacity. It's much more challenging for families whose sons, daughters, brothers or sisters don't have that capacity."

For Jess' part, she has been clear with her mum about her wishes, including saying: 'I want to leave things to my nephews.'

What are we concerned about?

How we support families who don't feel comfortable talking about death and dying

While Jo is very clear that she has no problem talking to Jess about any aspect of death and dying, she knows of other families who don't feel comfortable with this topic and some parents who will not discuss it at all.

Jo says:

"I feel for those parents - and understand how they feel - if they can't talk about it, but it will be a nightmare if you don't have arrangements in place."



Jo's advice:

"If you don't feel comfortable, find someone within MacIntyre or elsewhere to sit down with you and your loved one. Making sure your loved one is safe and secure when you are gone is very important."

How some families may feel about being involved in the Dying to Talk Project

We know that death and dying is a sensitive subject, and as Jo points out in relation to involving families:

"Some parents will object, their loved ones have enough to cope with. But to not mention it at all, and then it happens, could be devastating for a person with a learning disability."

Making sure we maintain effective communication with families

Given the sensitivity involved in talking about death, dying and planning for the future, Jo points out that some staff teams might benefit from improved communication skills. This is something we need to monitor and provide additional training for if needed.

How some staff may feel about death and dying

Although we've done extensive work with staff teams in our pilot areas in Phase 1, staff in other areas haven't had access to this training and may not feel comfortable with talking about and providing support related to death and dying. We hope - with more funding in the future - that we can roll out our Dying to Talk training more widely across MacIntyre services.

What next?

Phase 2 of the Dying to Talk Project – Jo's involvement

Jo will be involved in Phase 2 of the Dying to Talk Project, which will focus on working with the people MacIntyre support, their families and healthcare professionals.

Jo says:



“If I can help others by talking to them, explaining why planning for the future is important, then I will. Somehow every son or daughter supported should know that mum and dad will die one day.”

Phase 2 of the Dying to Talk Project – Jess’ involvement

Jess also wants to be involved in the next phase of the Project. Jo says of Jess’ involvement:

“She may cry, but to me that’s good. This is an emotional subject, and that’s ok.”

Suggestion of families being involved in staff training

As Jo says:

“Where families have experiences around death and dying that they are prepared to share, use us as experts by experience in staff training.”

Suggestion of a buddy system for families

Jo worked on a cancer helpline a few years ago, and describes a buddy system they had that connected someone newly diagnosed with another person who was going through the same experience (a ‘buddy’ who was fully trained) to provide peer support.

Jo says:

“It was really helpful for people to talk to someone who had gone through the same thing. Perhaps this would help family members within MacIntyre to tackle planning for the future with their loved ones.”