

Leaving home – a fresh new start

Eléonore, Felicity and Joffy are in their early 20s, and each has just left home. There's nothing unusual in that, except that all three are multi-sensory impaired: what's it like leaving home when you need lots of support?

SJ Butler spoke to families and professionals who have experienced this first hand.

Eléonore Spigel

No two deafblind people and no two families are alike. But Eléonore, Felicity and Joffy's stories show that there are many similarities in the challenges they and their families have faced – and in the positive experiences too.

For the parents of a young child with a multi-sensory impairment, it may seem hard to imagine that one day they will leave home. At home, they are understood, loved, and safe – who else can look after them so well?

But as their child moves towards adulthood, they may feel a need to live as independently as they can, control their own lives, make new friends and try new experiences – and families naturally begin to think about the future.

Josie Bell is Sense's Family Liaison Worker, supporting the families of deafblind people in Sense's residential services. In one family she works with, the young deafblind woman has for years been collecting the things she'll take with her to her own flat – and has very much led her family towards helping her to leave home. That doesn't stop her family worrying, but her desire for independence is clear and they know that leaving home is the right thing for her.

'As their child moves towards adulthood, families naturally begin to think about the future'

In another family, a deafblind young man was contented at home and had no concept of what it might mean to leave, but his family needed to consider his future and to make sure he would always be well looked after. For them, the challenge has been that they would have to make the decision for him.

Josie says that although this young man was unaware of the possibility of leaving home, "children become adults – they outgrow us". Just like any other young person, it was time for him to set up a life with people his own age



Joffy Haines

who would share his interests, and have the energy to try new things with him as well as support him. Despite his family's worries, he's happy, and leaving home has motivated him to become more independent.

For this young man's family – as for many others – the main reason they decided to look for a home for their son was to make sure that his future was secure. They wanted to help choose where he lived, and who would look after him when they were no longer able to do so. They needed to be reassured that without them he would still be safe, cared for and happy.

Eléonore, Felicity and Joffy left home either straight from school, college or shortly after, so their transition to adult life away from home has felt like a natural progression.

'Whenever a family decides it's time for their child to leave home, it's difficult. However, there are strong reasons not to put it off'

This isn't to say that the process of making the decision, finding the right home, obtaining funding, and setting everything up has been easy – no one would pretend that.

Nor has the emotional journey been gentle: families worry, have sleepless nights, stagger exhausted from battle to battle with funding bodies, deal with all the rest of family life, and above all, feel guilty that they're saying they can no longer care for their child.

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First and foremost, choosing a new home is a major decision. It's also a long, slow process. Ideally, the first conversations start as part of transition planning at school when the child is 14. However, in practice, many young people leave school with no plans in place, perhaps because they and their family want more time at home together, or can't imagine their son or daughter being able to leave home. Krystyna Cieslik, Sense's Assessment and Advice Officer's advice is simple: "Go out there, have a look, meet people, see what the options are."

Sometimes, a family never does feel it's the right time for a deafblind person to leave the family home and the result can be a crisis

Residential service or supported living?

Both residential and supported living services enable a deafblind person to live as independently as possible, with support. Sense's Housing Options Plan will help you to decide between them. There's more information on Sense's website.

when parents become ill, or die, leaving their deafblind son or daughter in the care of social services, with no one to fight their corner. In one go, they lose the people they love, their home, and the support they need. In order to avoid this, it's worth making plans, even if it's not yet time to put them into action.

When they're ready, with a plan in mind, the family can apply for funding and start to look for a suitable home. Sense will walk with a family every step of the way – providing not only advice and information, but also a shoulder to cry on, and a formidable presence when negotiating with funders.

Funding, as ever, is one of the greatest challenges. Josie Bell says, "Every family I know

has had a funding battle. For very few it's plain sailing and I can't think of one where it went to plan, especially now."

At a time when local authorities are under ever increasing pressure to cut their budgets, it's no surprise that they often try to find the cheapest options, but this can lead to the deafblind person receiving inadequate support or to being placed in a non-specialist home, perhaps with much older people. Local authorities vary, says Josie, and some place little emphasis on enabling a person to lead an active life: "If they can get away with a basic sort of care package, which literally means that people are fed and clean and dry and safe, then that will do."

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When negotiating funds, most local authorities will start at the lowest level, but it's clear that when they already know a family, and Sense is involved, there's more chance they will increase their offer. It's worth reminding them of the Deafblind Guidance, because it ensures

Some things to think about when choosing a new home

- Do you want to be near family, friends, or the place you went to school?
- Do you like living with a larger group of people, just one or two, or on your own?
- What do you like doing?
- How do you communicate?
- What support do you need?
- Does your mobility affect where you live?
- Do you like to be in the town or the country?
- Do you need specialist medical support?

that a proper specialist deafblind assessment is carried out. Some families have had to resort to legal action.

Korrina Campbell, Sense's Head of Business Development, is targeting local authorities, helping them to identify young people as they approach school leaving age, and – armed with the young person's housing options plan



Eléonore Spigel

Eléonore is 22, and lives in Manchester. She has severe learning difficulties, impaired vision and hearing, poor muscle tone, and severe and unpredictable epilepsy.

Eléonore lived with her family in north London until she was 19, when she moved to the college at the David Lewis Centre for Epilepsy, near Manchester.

As Eléonore got older, and her epilepsy more severe, the Spigels knew she needed to live somewhere with intensive, specialist support. Her father, Robert, could no longer take her out on his own, or carry out personal care, and their fourth floor flat wasn't accessible when Eléonore was in a wheelchair – she has broken her leg several times during seizures.

This year, Eléonore moved into a small flat on the college campus to prepare for her transition. Soon, she will move into a refurbished house on site which she will share with two other young women and their

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carers. The house is registered as a care home.

It's not an easy thing to decide, but, says Robert, "You've got to learn to let go, because nobody can do it for you."

Robert says that they have grown used to Eléonore being away from them: she went on Scout camp, and Sense holidays, so "although it's been traumatic, it wasn't totally new." In the long term, too, he says they had to make plans for Eléonore's future: "We both realise that we're likely to die before Eléonore does. If we don't get her used to doing without us on a daily basis, it's too late when we're dead."

Robert says that one of the biggest challenges for him

has been learning to bite his tongue when he sees support staff doing things for Eléonore that she can do for herself such as picking up something she's dropped on the floor or putting on her car seat belt.

With Camden Social Services, the Spigels produced a DVD about Eléonore to help new staff understand her. It talks about her disabilities and the help she needs, and shows Eléonore having a seizure as many staff won't have encountered one before and it can be frightening.

Eléonore has adapted well to being away from her parents: "Though Eléonore's delighted when she sees us, on the whole when you see her with other people, she's happy and laughing and very positive."

– to look ahead to the accommodation they will need.

She has a national view so, for example, can help three college friends to find a home together, or another to find a flat near their parents. Above all, she says, it's about finding the right home for each person, rather than slotting them in where there is a vacancy.

Finding a home in the right place has always been a challenge for deafblind people and their families, so this summer Sense began working with Golden Lane, a national housing

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association specialising in homes for people with learning disabilities, which opens up many more options for people looking for supported living.

Once the deafblind person and their family have found the right place to live, there's still often a great deal of preparation to do. The key to success, says Josie Bell, is plenty of communication and collaboration between the family and the staff in the new service: "That's what really works, and what makes a difficult process bearable."

Karen Elsbury, who manages Sense's supported living projects, says that it's helpful for families to know that they're not closing the door on their child the day they leave home – they can always return home. Also, she says – unlike children who go away to university or to a new job – a deafblind child who's unhappy is far less likely to hide their unhappiness: they will communicate it, quite



Felicity Stafford Allen

Felicity is 23 and lives in East Dereham in Norfolk. She has a rare genetic degenerative disorder. Felicity has lost her vision, mobility and speech and now needs intensive support 24 hours a day.

Felicity lived with her family in Kings Lynn until she was 19, attending local schools apart from four years as a weekly boarder in Kent. She now lives in her own bungalow with live-in support from Sense, where she will soon be joined by another disabled young woman.

Her father Gus says "There's never really been a prognosis – it's been difficult to know what to expect and therefore we've had to take things as they've come, and deal with them, and so has she."

They were finding it harder to look after Felicity themselves, even with the help of carers: Gus's back was injured, and, as Gus says, "It's fine when you're in your 20s and 30s, but when you're in your 50s and 60s you don't really expect to be up two or three times a night".

Her mother, Julia says, "We wanted to be able to set Felicity up independently of her siblings so that if we went under a bus, her life wouldn't be disrupted, there would

be continuity, nothing much would change other than that she wouldn't see us. We felt it was time to do something. As well as the fact that I was acutely aware that Felicity didn't really want to live at home. She didn't want to be with her boring parents."

It was a stressful time. Felicity's new adult social services team were talking about placing her in a residential service with much older people, so they applied to become Felicity's legal guardians and this gave them back control.

Gus says, "We came at this from a position of almost total ignorance and without Sense leading us through it all, we would have been truly lost. It's made us think, how do others manage who haven't got that level of support that Sense give? How do they manage to get through this maelstrom of red tape and local authorities?"

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Handing responsibility for Felicity's care to Sense wasn't difficult: "We'd had a relationship with Sense for so long, we trusted Sense staff. We feel we're on the same wavelength, and that's a great comfort. There's a lot of empathy."

Although they agree that it's hard to shake off the feeling of responsibility, and Gus says that they feel guilty at "subcontracting our responsibilities" they both see many benefits: Felicity has a much more interesting and varied life, Gus and Julia are less exhausted (Julia's friends say she looks 20 years younger), and the whole family enjoy having more time together.



Leaving home can help people like Selina Hill to spread their wings

possibly through strong behaviour. And if this happens, the team will find out what the problem is, and address it.

'Eléonore, Felicity and Joffy are thriving in their new homes'

Even knowing this, when a disabled child leaves home, it's a time of transition for everyone in the family. No matter how happy the young person is in their new home, almost every parent feels guilty. Krystyna says, "Unlike another young person who makes their own choice to leave, you're making the decisions on their behalf. How do you know what the right decision is? You feel as if you're pushing them away and you feel bad about that."

But it can be a positive move: Eléonore, Felicity and Joffy are thriving in their new homes. And while it's true that after years



of being fully involved in every aspect of their son or daughter's life, parents' feelings of responsibility may never fully go – their relationship with their child will change. Their role as carer will fade and they can build a parent-adult child relationship where each can simply enjoy the other's company.

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Find out more

- Sense's Information and Advice Team: the first point of call when thinking about leaving home. Tel: **0845 127 0066** email: info@sense.org.uk
 - *Supported living – making the move*, Alicia Wood and Rob Greig, NDTi, 2010, www.ndti.org.uk: Lots of information about different ways to fund supported living.
 - *Leaving Home, Moving On*, Nigel King and Maurice Harker, The Foundation for People with Learning Disabilities, www.mhf.org.uk: clear guide for young people and families
 - Housing options: free factsheets about all forms of housing: www.housingoptions.org.uk
 - Golden Lane Housing: Ground Floor, West Point, 501 Chester Road, Old Trafford, Manchester M16 9HU; Tel: **0845 604 0046**; email: enquiries@glh.org.uk www.glh.org.uk
- NHS Continuing Healthcare: <http://www.nhs.uk/chq/Pages/2392.aspx>

'Ultimately, though Debbie is convinced they've done the right thing for Joffy. He's more independent, does more things because the staff have more time'

Joffy Haines

Joffy is 20 and is deafblind and has other disabilities. He moved to Tanglewood, a Sense residential service in Malvern, this April. His parents, Debbie and Mike, live 45 minutes' drive away in Solihull. He has two brothers, Chris and Andrew.

"It's been quite a year," says Debbie, "Chris has graduated and come back home, Drew has gone to university, and at the same time, Joffy's gone to Tanglewood."

Since Joffy moved, Debbie says, "My other boys have noticed that I'm less stressed, and we have more time for them. It's definitely an improvement, but when we go out and do something as a family, there's always one missing. When my older son left home to go to university I didn't miss him in the same way – the difference is that Joffy didn't choose this, we chose it for him. But I do 100 per cent believe it's the right place for him."

Debbie hadn't planned for Joffy to leave home until Sense suggested he go on a Sense holiday, which would be their first time apart. He thrived, and she began to think about where he might live as an adult.

"We'd got to a bit of a crisis point where I was absolutely exhausted. It was Joffy's teacher who said – tell your social worker. Once I said I was really struggling they were really good. You do have to have a bit of a crisis and become a bit more emotional than I would like."

They knew they were looking for a residential home as although Joffy likes his own space, he also likes to live as part of a family. Debbie also felt that a small team of support workers might struggle with the intensity of caring for Joffy.

They found Tanglewood and Joffy went for visits. Debbie and the staff met many times to plan and share information, and then they were ready and Joffy moved in. Debbie found it hard at first, not knowing exactly what Joffy was doing, or how he was, but staff rang her and sent texts every day, and sent photos occasionally, and she feels increasingly confident that

he is all right. She trusts the staff, and feels that they are getting to know Joffy well.

It was strange, no longer having to plan her days around Joffy: "When Joffy first went away I felt completely redundant. The first week was OK – like a Sense holiday – but after that I didn't know what to do with myself. Friends suggested hobbies, but I hadn't had time to have any."

"I miss him terribly, but part of me doesn't miss the restrictions that caring put on me – now I can walk the dog, or have tea with a friend. And there are certain aspects of the caring – this is going to sound horrible – that I'm not going to miss. But it is hard when they don't need you."

Ultimately though, Debbie is convinced they've done the right thing for Joffy. He's more independent, does more things because the staff have more time, and she knows he's ok because when they take him back to Tanglewood after a visit home, he doesn't cling to them: he's impatient to get in the door and make himself a cup of tea.

