Top Tips when supporting someone with learning difficulties in talking about loss and grief.

This is based on my client contact with Alex ( not his real name) who had lost his mum in 2015 and witnessed his twin brother’s death from a massive heart attack in 2020-during lockdown and in the house he shares with his dad who is over 70 years of age. After his mum died, his older brother (who also has learning difficulties) became aggressive and moved out of the family home into supported living. There is no contact between Alex and his older brother as he is frightened of his outbursts which were possibly his way of expressing his own sense of loss. Alex was very close to his twin and had not talked about his death. He is scared of what may happen next but does not want to upset his dad by talking about his fear or the future, especially what will happen when he too dies. As both losses occurred during the summer months, Alex does not like that time of year and is waiting for the winter to arrive.

1. Brief yourself well before the first contact-the assessment may not give vital details, for example, communication style, preferred name, support needs.

Contact was made via telephone, initially with dad with Alex in the room. Dad gave an overview of the situation (from his perspective) and I was careful to get consent from Alex to talk to Dad and for him to be present. This is complicated by the fact that I did not know Alex’s needs and whether he could use the phone or understand the purpose of my role. Dad was essential in terms of setting up the appointments as I was not sure of Alex’s concept of time, making appointments etc.

1. At the first session we agreed the method of contact in the absence of face to face. Alex uses a computer so I offered sessions on Zoom so we could see each other. This was important for being able to observe Alex’s body language, his interaction with his dad who was always present but especially because due to his poor mental health (exacerbated by grief and social isolation), Alex was hearing voices. I felt talking over the phone would add to this and that he should see me in the hope that we could establish a better rapport based on audio and visual signals. I talked about eventually meeting face to face whenever possible and Alex responded well to the idea.
2. Keep to the appointment time-often very important to people with autism but also a polite recognition for all clients. I had a backup plan if Zoom failed. I sent invitations via a Cruse email to ensure my confidentiality and rang during the first session to advise Dad how to install Zoom and turn the camera. IT connectivity can be a problem especially bandwidth. In the event on Zoom not working we agreed to use the phone and keep the session time.
3. Be mindful of time in terms of the length of the session. Dad wanted to update me regarding Alex’s support (or lack of it) and I had to ensure that I only spoke to Dad with Alex present as ‘nothing about us without us’ is a mantra I follow in terms of the people first (self advocacy) approach. Timing can be difficult in terms of an individual’s attention span and coping with previously unexpressed emotions, so pace each session to the client’s needs and ensure that you do not overload the client. Too much talking can be emotionally overwhelming for the client and Alex’s dad commented that he had never heard Alex speak so much. He had become withdrawn after his Mum’s death. At the outset Alex was concerned about how many times he could talk with me but I was careful not to state a fixed number of sessions, recognising his particular need for building trust and being able to express himself. I felt that flexibility was needed.
4. Focus on one issue at a time. Once Alex started talking it was like the floodgates had opened and he was very animated. It is important to use common language, words that matter to the client and to keep it simple-not in a patronising way but to allow expression and clarification.
5. Find a way in; the hook. Our first session was bizarre (to me)as Alex talked about the Masters of the Universe and I realised that his interest in this had become his way of trying to make sense of his brother’s death and where he had ‘gone to’. For the next session, I researched the topic (as well as Star Wars) so we could have a discussion around what was meaningful to Alex and to use as a metaphor for understanding his loss. We decided Luke Skywalker as a ‘goodie’ could look after his twin brother and save him from the ‘baddies’. During our contact the Euro 2020 football was taking place and Christian Erikson had a heart attack on the pitch. This was similar to what had happened to Alex’s twin brother and we used it as a way to talk about sudden death, emergencies, the role of paramedics and the need for defibrillators. This appeared to help Alex better understand what had happened, tell his own story and how he could only do what he had done.
6. During our sessions, fear of anniversaries and the time of year came up. People with learning difficulties often live in the present and relate to triggers. This is not just relevant to certain clients but putting grief into context and explaining the importance of memories and anniversaries can be helpful to help clients normalise their grief. Of course, shielding and isolation during Covid had meant that Alex had not had his usual routine and he had more time on his hands. Signposting to social activities would help Alex to move forward but this had been complicated by the lack of support.
7. Despite the Care Act 2014 and the need for support, I established that Alex’s social care package was one hour per week which involved a home visit and learning (repeatedly) how to make a cup of tea. Many professionals had been involved with the family over the years and someone had mentioned Alex moving to supported living before his Dad dies. This was not just crass and unhelpful but clearly added to Alex’s anxiety. None of the actions appeared to have been put into context or explained to Alex, for example, a nurse had asked him to keep a drinks chart but without saying why. Apparently, it was to monitor Alex’s consumption of fizzy drinks which was quite considerable. As his anxiety and difficulty with sleeping could be linked to caffeine levels, I was able to suggest he reduced his intake especially after 6pm and why this may help. Similarly a chat about his bedding and the use of a winter duvet in summer resulted in Alex buying a lightweight duvet via Amazon and this reduced his sweating at night time. Often basic or practical suggestions can help improve health and wellbeing. Adopting a holistic approach allowed Alex to better understand how things connected and reduced his state of anxiety.
8. I discussed GP contact as he had referred Alex to Cruse. It appears that Alex has monthly check ups and trusts his GP although it did appear that the GP talked to Dad rather than Alex in a kind of ‘does he take sugar’ way. We discussed trauma and sudden loss; given that Alex was having flashbacks often triggered by TV stories, I suggested that he spoke to his GP about PTSD and whether he could be prescribed medication or referred for CBT. This is an ongoing discussion as Alex has been referred to a psychiatrist which reinforced a different approach to his grief and increased his anxiety as many years before Alex had been sectioned and his experience of that time was too traumatic for him to even think about. Grief when you lose someone is completely normal-labelling Alex as having a mental health issue is not helpful and can lead to an over dependence on medication and reliance on a medical rather than adopting a social model of disability. I referred Alex to a local charity offering talking therapy, mindfulness and possibly CBT. I also gave Alex information about the lone twin network.
9. Alex’s fear was as much about living as coping with death and dying. His world had shrunk by 3 people (including his older brother whom he had seen ‘removed’ from the family home) and literally into 4 walls with fear of what/when/if his dad died which was a pressing concern. This could trigger even more loss including his home and familiar surroundings. Talking about the future with so many Health and Social Care professionals can influence and define the outcomes for people like Alex and it can be difficult but it has to be addressed as ‘the elephant in the room’. As a social worker myself for over 40 years, I encouraged Alex and his dad to think about what they wanted and ask their social worker to contact me. Although I have to be clear about which ‘hat’ I am wearing as a Cruse BV, I also have a duty of care to offer support, advice or information especially in the light of my experience of working with adults with learning difficulties. At the time of writing, a multi-disciplinary process has been put in place and discussions are ongoing about Alex ‘staying put’ with support moving in to support him to share his 4 bed house when his Dad is unable to look after him. In the meantime and in order to get Alex used to paid support (and give Dad some respite) there are plans to offer more hours of support in situ each day. This plan for living is vitally important when someone has lost much needed support. His dad due to age and his own needs is going to have a carer’s assessment.

This final tip is about maintaining clear boundaries, communicating actions taken, signposting where necessary but most of all active listening in a person-centred, valuing way in order to allow the client (regardless of any learning difficulties) to express themselves, hopefully empowering them to move forward and live well. Getting consent to advocate on their behalf as an ally or supporter is essential.

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