

SUPPORTING PEOPLE WITH AUTISM TO LIVE THEIR LIVES

Staying independent and at home

Paul

Background before support

Paul is 55 years old, he was suspected of having autism years ago but does not have a diagnosis. He has lived in his family home his whole life and with his mother Doris for the last 10 years since his father's death. Paul has lots of contact with people online (playing online games with gaming communities) and Doris writes emails regularly to her cousins, otherwise they have very little with the outside world. When Paul ran some errands for his mother when she was too ill to go out, otherwise he never leaves the house without her. He can catch the bus and go to the shops, but finds this stressful and returns to the house angry and distressed, often locking himself in his room for many hours, shouting and banging the walls.

A local police officer visits to investigate reports of shouting and banging coming from the house. The neighbour advised that she was concerned that she hadn't seen Paul since an ambulance took his mother away the previous week. The house appears to be in darkness and the curtains are closed. The police officer knocks on the door, he can see Paul through a crack in the curtains and can hear him moving around. The police officer calls to Paul through the letterbox to open the door.

Paul responds but refuses to answer the door. He is in the house alone. He has eaten all the food in the fridge and has hardly slept. He is becoming increasingly distressed and does not know what to do.

The skills, competences and knowledge to make a positive change

The Police

The Police Officer has had awareness training on Autism and on Mental Health. He was not sure what the problem was but realised that Paul was upset and needed some help. Due to his training, he knew not to ask lots of questions as this could result in Paul becoming more anxious and agitated. He clearly and calmly told Paul that he was not in any trouble with the police and that he was an officer and wanted to help.

The police officer made sure he asked key questions one at a time and clearly so he could gain a better understanding of the situation. He confirmed Paul's full name and what he preferred to be called. He asked if Paul was in the house by himself, if anyone else lived in the house with him and if there was anyone he could contact that Paul could speak to. Paul said the name of the doctor that visited his mother at home but didn't know how to contact her, he also said he didn't know where he mother was. The Police Officer asked if he could contact the GP and Paul agreed. The Police Officer made arrangements for the GP's surgery to be identified, contacted and advised of the situation.

The GP

The surgery knows Paul and arranged for the GP who was on duty, to attend his house as a priority. Although Paul doesn't have a diagnosis, his family doctor has long suspected he is autistic so uses skills and techniques that she thinks will help. The GP reassures Paul, reminding him that she visited his mother and asked if she could come into the house to talk to him, which he agreed. Clearly and calmly she advised Paul that his mother was very ill and was in a hospice, probably in her last days of life. She would not be coming back to the house. Paul was upset and distressed, this had not been clearly communicated to him before.

The GPs primary aim, was to make a risk assessment of Paul's ability to cope staying in the house alone in the immediate future and whether his distress and confusion placed him at any risk of harm. She believed that Paul's emotional response was understandable and that he was not at immediate or significant risk of harm associated with his mental health needs. However, she identified that he would need some help to come to

terms with his impending bereavement. The GP asked to see Paul a few days later to see how he was getting on and he agreed, during which time she planned to explore options for bereavement support appropriate to his communication needs.

Paul was very clear that he wanted to see Doris but was unsure where to go and had been scared to leave the house in case he couldn't get back in. His mum always had the door key and was there to let him in when he went out. He was also clear that he wanted to stay living in his house and became agitated at the suggestion of having to move.

Through her discussion with Paul the GP learned that he was not eating, drinking or sleeping properly. All the food in the fridge had been eaten and he was staying up all night on his computer. Further questioning led her to realise that, although capable of carrying out all the tasks associated with self-support, he had always been prompted by his mother of what to buy, cook and when to do things, including going to bed. She told Paul that in her opinion he would need some help to stay at home. As there were no friends or immediate family to provide this, she could ask social services to make an assessment and see if there was any support that they could offer.

The Social Worker

The GP made an urgent referral to the local adult social care team due to the immediate risk of self-neglect and the risk of his situation getting worse and leading to Paul having to leave his home involuntarily. She made it clear that, in her professional opinion, leaving his home would have a fundamental negative impact on his health and well-being. Residential care was inappropriate due to his intolerance of strangers or groups of people. Also, she believed he had the skills to stay at home, as he looked after his mother before she went into hospital. Most critically, on the evidence she had before her, Paul had the mental capacity to choose where to live and how to be supported.

A social worker that had received specific training in undertaking assessments of people with autism attended the house with the GP so they could be introduced. The GP supported Paul to tell the social worker about his recent change in circumstances and the support she would be providing and finding to help Paul with his mother's imminent death.

Paul felt comfortable with the Social Worker because he was patient, asking clear questions that Paul could understand and didn't try to do everything all at once. Instead the Social Worker focused on Paul's immediate care needs, particularly how he would eat, drink and sleep over the next few days. With Paul they made a timetable of when Paul would eat, sleep and have a drink in the next 24 hours and planned some meals that Paul could make based on what was in the cupboards. The social worker helped Paul to do an online grocery shop that would arrive the next day. He then gave Paul telephone numbers to call in case he needed to talk overnight; a local community support provider and the Samaritans - the social worker also advised Paul that he would contact a local community outreach team to see if they will provide him with some practical and emotional wellbeing support in the short term, during this difficult time.

Once Paul was reassured that no-one was going to force him out of his home, he felt able to accept an offer of help to go and visit his mother. The social worker helped him find the door key so that he was in control of locking up and knew he could get back in. They went in a taxi to the hospice and Paul was able to spend time with his mother and the social worker was able to tell her that Paul would have help at home. He also explained to the hospice staff that when she died they would need to inform Paul using very clear language and, with his consent, they should also inform the social worker. He then he travelled back with Paul, collecting fish and chips on the way home. Paul's Mum died during the night and the hospice staff informed Paul by telephone, contacting the social worker first thing in the morning.

The social worker visited Paul to offer comfort and provide support. He noticed that Paul had received a lot of post and asked if he opened letters or if his mother used to do this. Paul confirmed his mother opened the mail and would complete forms, so the social worker asked permission to go through them with Paul to make sure there wasn't anything urgent. They found a letter from the solicitor who Paul's mum had seen to make her will a few weeks earlier. Paul's mother left everything to Paul including the house, Paul agreed that the social worker could speak with the solicitor to ensure any questions regarding the house were answered correctly.

The social worker assessed that Paul needed some immediate short term support to make sure that his essential health and wellbeing needs were being met and to help plan his days and tasks to continue to live independently in his own home. He also identified that an advocate would be helpful to support Paul in the ongoing arrangements with the solicitor. The solicitor advised he would now act for Paul in the matter of the house.

Paul was able to use online forums to get help to come to terms with his bereavement.

The Community Outreach Support

The social worker appointed a team that provided practical short-term support in the community. He knew by experience that they were autism-aware and delivered person-centred approaches so Paul would be fully-involved in helping to develop his support plan.

The community support worker also helped him think about what needed to be done in the house to make sure it was a clean and healthy environment to live in. As with cooking, they established he could do most domestic tasks but needed support in their planning.

The social worker also contacted welfare rights to make sure Paul had enough money to pay his bills and what he might need to do regarding his inheritance and his benefits. The welfare rights worker understood from the social worker that Paul could not respond to letters or complete forms so was prepared to support him in this.

Outcome achieved for Paul

Paul stayed in his family home.

Supporting outcomes

- Paul received support that gave him the time to make his own decisions and cope in his own way.
- The professionals worked together so Paul didn't have to keep repeating himself and was introduced to each new person so he understood their specific role.
- Paul's grief was recognised and was supported to manage his grief and anxiety that worked for him,
- He received the right support at the right time, focusing on his immediate needs.
- Once the immediate needs were met a medium-term plan was developed that focused on his strengths and his choice to stay at home.
- Although Paul didn't have a diagnosis those involved recognised that he may be autistic and took this into account when working with him.