

# **SUPPORTING PEOPLE WITH AUTISM TO LIVE THEIR LIVES**

**Supporting positive health  
and well-being in older age**

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**Gordon**

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## Background before support

**G**ordon is 70 and has suspected autism and is aware of his challenges. He has a strong family history of autism and has two grandchildren with Asperger syndrome. He is a retired history professor who lives alone at home very independently. He drives a car and is normally socially active at the golf club. His wife died 2 years ago. Over the last 18 months Gordon has stopped attending his diabetes follow-up appointments with the Practice Nurse and has become progressively more chaotic, attending the practice in a “crisis” without appointment and being rude and aggressive towards reception staff which is out of character.

Gordon has lodged 4 complaints in the last 6 months regarding members of staff at his GP Practice, all associated with clashes with reception staff over having urgent appointments and access to care he thinks he needs at that time. He has recently started to turn up at A&E, calling for an ambulance or going to the Walk-In Centre regarding issues that could easily be dealt with by his GP or local pharmacist. His GP receives letters from the out-of-hours Walk-In Centre and A&E regarding Gordon’s “inappropriate” behaviour and use of services and also, highlighting the GP’s role in monitoring his diabetes, concerned that his blood pressure and blood sugars levels are unstable. Gordon’s family live locally but are unaware of his difficulties as he is so independent and says everything is fine.

The Practice sent a letter to Gordon inviting him to come in to talk to his GP about any issues that may be preventing him from attending their diabetes clinic. On receipt of the letter Gordon was not happy and visited the Practice with the letter, demanding to be seen immediately and was shouting and complaining loudly in the waiting room. One of the GPs came to diffuse the situation. She saw that Gordon was angry but also extremely distressed and agitated, surrounded by lots of patients with crying babies and children playing.

## The skills, competences and knowledge to make a positive change

### GP and the Waiting Room

The GP has had autism awareness training and recognised that Gordon might have been overcome by the multiple visual and auditory stimuli of the waiting room. This, in addition to his anger and anxiety from coming into the Practice, appeared to have built up into a meltdown. The Practice was attempting to become more autism-friendly and had developed a quiet room that people could generally access when they were upset. The GP took Gordon there and gave him some water, allowing him some time to feel more settled and some space should he need to go through some coping strategies or routines. She gave him time to gain control and did not interrupt or try to touch him.

The GP asked calm, clear, short and direct questions to ascertain the problem and reflected back to Gordon her understanding of his upset and anxiety before discussing possible remedies. She arranged a 20-minute appointment for Gordon with a GP of his choice at the end of the day when the waiting room and practice would be quieter. She suggested that he write down the key concerns he wanted to raise and bring it along when he returned later in the day. Gordon agreed.

### GP Consultation

Gordon attended the GP appointment and his GP took time to let Gordon talk and express his frustration, anxiety, loneliness and grief. The GP learnt that Gordon’s wife had always made appointments for him (including attending the diabetes clinic), all of which she would arrange for the end of the day when it was quieter. She had also arranged his prescriptions for his medication and, it further transpired, opened and dealt with all of the post they received.

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Gordon was unaware of how to make appointments or attend the routine diabetes clinic, resulting in him going to different places to get help. On arrival, however, he found the places disorientating and overwhelming and he couldn't communicate his needs, often coming across as aggressive and being misunderstood. He wanted to know what to do. He was happy to follow a new routine but was unsure as to how to go about planning one. He was deeply embarrassed and felt out of control.

The GP reassured Gordon that he understood, that it was clear that in addition to grieving for his wife Gordon had lost the structure she had always provided and it was therefore understandable that he felt lost and out of control at this time. The GP arranged for Gordon to spend some time with a Practice Nurse developing a timetable that would become the new framework for his healthcare plan including attendance at the diabetes clinic and ordering repeat prescriptions. The GP also wanted to make sure that some of Gordon's 'behaviours' were not associated with him being unwell or that his diabetes was not uncontrolled so he reviewed him whilst he was in the Surgery.

The GP Practice did not have a Practice Therapist so the GP offered several appointments for Gordon to come in so she could monitor his grief-management and how he was coping over a number of weeks (planned in advance), also preventing him from overburdening Gordon in one session. During these sessions, Gordon was given time and space in a non-threatening environment to express his grief, the challenges he faced and how to move forward. The GP asked Gordon if he believed he was autistic and, whilst he didn't want to go through a formal process of diagnosis, he recognised that the structure and approaches helped him a lot and felt he probably was "somewhere on the spectrum."

To update his file the GP also asked for Gordon's next of kin. It was suggested he might rekindle contact with his family and explain what was being done to try and rebuild some structure in his life, something they may be able to help with. Gordon thought this was a good idea now he felt more in control, and that he hadn't wanted to burden them before. The GP reminded Gordon that his family would also be missing his wife and that by sharing stories together it will help with the grief and loss. On returning home Gordon contacted his son who visited him at home and brought his grandson who helped him use his iPhone calendar for appointments and organising his week with reminders and prompts.

## **Practice Nurse**

The practice nurse met with Gordon and discussed the follow-up arrangements for his diabetes. She wrote everything down to take away as well as a diary handbook that the nurse would complete at future appointments. She asked if they could send reminders of future appointments to his mobile and he thought that was a great idea. The nurse stressed how important the routine follow-up was and how it would help him. The practice nurse agreed to see him over the next 6 months to re-establish control over his diabetes so that he only had one person to deal with. Gordon was advised about how to get his blood tests prior to seeing the nurse and this was included on his plan.

## **Practice Administration**

A member of the Practice administration met with Gordon and discussed the various methods of obtaining appointments that Gordon might find easier (i.e., internet or popping-in at end of the day or first thing in morning). She advised which appointment slots might work best and agreed with Gordon to put a marker on his records to show the priority slots for him so he could access end-of-session slots without question. He was also given a telephone number he could call for emergencies and asked if he would be able to email non-urgent questions to save him coming into the surgery. She advised him which days to try and avoid if possible (e.g., baby clinic days) and how the patient call system worked in the waiting room.

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He was also reminded of the quiet space and told to use it if he felt he needed to. It was suggested he bring a book he could get into or the Telegraph crossword (a weekly routine occupation and enjoyment for him) when he came. Gordon was further provided with a Practice prospectus and the Practice also decided to produce an autism-friendly brochure with clearer instructions and no adverts.

## Outcome achieved for Gordon

Gordon's health needs have been reviewed with new plans in place to best support his health and well-being going forward in a way that he can manage.

His grief has been recognised and the impact this has had on his life emotionally and practically.

## Supporting outcomes

- Gordon was able to access medical service appropriately and take control of his diabetes.
- Gordon was able to express his frustration, fears and concerns in a positive experience that helped him to problem solve with the GP and Practice, developing a bespoke team approach for him to access his medical care.
- Given sufficient time and support Gordon was able to work through his grief and address the challenges losing his wife raised in a way that made sense to him.
- The Practice worked together so that Gordon didn't have to face different individuals all the time and could avoid the waiting room at peak-times.
- The Practice had a look at their Practice brochure and decided to develop an autism-friendly version.
- Immediate and long-term needs were able to be addressed due to a team approach including Gordon.
- The practice placed autism awareness training and adjusting the Practice to be more autism-friendly firmly on the agenda.
- Gordon was encouraged to be more self-aware and adopt a "toolkit" of de-stressor activities when needed.
- Gordon developed approaches that were useful to him through his contact with his family and autistic grandchildren.
- Gordon felt less isolated which had a positive impact on his emotional wellbeing.