

HCP / Caregiver(s): Mum and Dad – you can reach them at ph

My Short Story



My name is	Bob
My birthday is	05/02/2010



My favourite things to do	Pat my dog, have cuddles with close friends and family, eat ice-cream	
When I am happy I	Get excited, laugh and flap my hands	
I can do these things for myself	Eat, drink, walk, watch TV	
My favourite foods	Ice-cream, mince and pasta	



I don't like to	Be left alone in a crowd, hear lots of loud noises	
When I am worried I	Wring my hands and sometimes rock and cry	
I need help with	Getting dressed, staying warm or cool with changing temperatures, going to the toilet, following instructions, basic hygiene	
My least favourite foods	Most vegetables	



About me & how to help



Urgent care is required when

I have seizures - See my seizure management plan

Pitt-Hopkins syndrome

Describe symptoms		How to help
Mobility & stamina	I have reduced coordination, strength and energy levels	Take time to explain activities, allow extra time, stand by to assist and let me have frequent rests if I'm tired
Communication and comprehension	I understand more than I can express I get confused with lots of instructions	Take time to explain, use simple one-step instructions, check that I understand
Behaviour and sensory processing	I have sensory processing difficulties - Loud noises & crowded places make me feel scared	Check me after falls, trips or other accidents- Stay close & reassure me
Eating and drinking	I can drink & feed myself	Prompt hand washing before meals
Toileting and hygiene	I need help to manage my bladder and bowels	Take me to the toilet regularly (no more than two hours between visits) Prompt & supervise wiping myself and washing hands
Breathing and sleep	I sometimes breathe quickly and irregularly	Watch more closely and help me to sit down, this may trigger a seizure

