

Table SI. Selected quotes for "unnecessary treatments and procedures" and "symptom triggers"

Theme	Example quotation
Unnecessary treatments and procedures due to inaccurate diagnosis	"At first they thought it was some kind of arthritis. I was given methotrexate as treatment."
	"Before being diagnosed, I used to be given all sorts of things. They treated me for ulcers and appendicitis. They diagnosed me with a lot of other things. I had surgery for appendicitis, but because the pain continued, they thought it was intestinal adhesions, so they operated on me for that. Then they operated for that a second time. Then they told me it was reflux. But none of the treatments helped with the pain."
	"Before I got the diagnosis – I had been treated for allergy all my life with all kinds of strange medications. I have seen quite a few emergency rooms all over Denmark, I guess. That was very stressing, also for my wife."
Symptom triggers	
Accident/injury/ trauma	"I was diagnosed after I had a traffic accident. My face swelled a lot because my left cheek hit the steering wheel. I applied ice but the inflammation grew and I went to the hospital. They didn't know why the swelling wouldn't go down."
Disease/illness	"Now I caught a cold from the toddler...and well, it's fairly constant....Any cold or anything that makes my body react will lead to an outbreak of angioedema."
Physical activity	"My swellings are in hand (e.g. after I have cleaned the windows) and feet (e.g. after I have worn high heels)...."
	"If I ski, I will most likely have an attack because I always fall, and when you fall you have an attack. And riding a bike, just sitting on the seat will give me an attack."
Stress	"When I wasn't well-controlled, I lived with fear when there was any sort of disappointment or situation or event in my life that provoked a bit of tension, knowing that there was a risk that it would produce an episode."
Pregnancy	"In the first 2 trimesters I had [attacks] every 10 days, now, in the last trimester they occur less frequently, i.e. the last attack has been the first in 4 weeks. Maybe my body has adjusted to the pregnancy better now."
Certain medications (including hormone therapy)	"Until a few years ago, in 2007, when they diagnosed me with breast cancer, the attacks were very rare. However, because of the medicine, a hormonal treatment, I started getting attacks every 5 days."
	"It would be good to have learned about the link between HAE attacks and estrogens sooner. I only became aware of this link because of my pregnancies, but it would have been good if somebody had told me earlier. Only recently I was told not to use oestrogen-containing contraceptives. This will also be relevant for my daughters when they are old enough to use contraceptives."