

Patient story: living with hidradenitis suppurativa and pilonidal sinus disease

KEY WORDS

- ▶▶ Hidradenitis suppurativa
- ▶▶ Pilonidal sinus disease
- ▶▶ Quality of life
- ▶▶ Cost of care
- ▶▶ Managing the condition

Becky Smith lives with two challenging skin conditions, hidradenitis suppurativa and pilonidal sinus disease, which cause lesions/abscesses. These chronic inflammatory conditions usually affect individuals in their 20s to 40s and can have a huge impact on patients' quality of life. Depending on severity, management of these conditions includes lifestyle, psychosocial, medical and surgical interventions. Becky has adapted her lifestyle to best manage her conditions. She recognises the early warning signs of an onset of hidradenitis suppurativa and promptly seeks treatment. Following two operations for pilonidal sinus disease, she is now hopefully free from this condition. Here, she explains in detail how the conditions have affected her and the mechanisms she has learnt to cope with them. She hopes that illustrating her journey will help other patients with these diseases and lead to a better awareness of the conditions among the healthcare staff who manage them.

Becky is 36 years old and has developed hidradenitis suppurativa (HS) and pilonidal sinus disease (PSD) within the past 6 years. Her HS has been managed, for the most part, in primary care with high-dose antibiotics, and she has made several lifestyle changes to reduce its impact on her health and wellbeing. Her PSD has required surgical management. Since her diagnoses, she has become an expert patient and is now using her experiences and knowledge to help others.

HIDRADENITIS SUPPURATIVA

Hidradenitis suppurativa (HS), which is also known as acne inversa or Verneuil's disease, usually affects areas of skin containing pilosebaceous glands (Hidradenitis Suppurativa Trust, 2018). Over the past 6 years, Becky has developed lumps under her arms, on the breast and around the groin area, which are areas commonly affected by this condition (Ferris and Harding, 2019).

HS is associated with smoking and obesity (Young, 2018); however, Becky is a non-smoker, is overweight (not obese) and has a fairly healthy lifestyle. HS is thought to have a genetic

component (Young, 2018; Ferris and Harding, 2019) and Becky's sister also suffers from it. Her sister's presentation is much more severe and has resulted in 33 surgeries in the groin area.

INITIAL PRESENTATION

Becky's HS first presented itself in April 2013, when a painful lump developed under her left arm. She made an appointment with her GP, who lanced and drained it and prescribed some antibiotics. When another lump developed 2 months later, Becky's GP decided against lancing and referred her to the hospital, where she was prescribed co-amoxiclav.

ONGOING MANAGEMENT

Since 2013, Becky has developed a number of lesions. Most have been in her armpits but on occasion, lumps have occurred around the breast bone and in her pubic region, with the latter typically appearing before her period starts. A day or so before a lump becomes visible, she experiences psychological disturbances which she describes as being similar to premenstrual tension; during this time, she may feel down and

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Figure 1. Surgery for pilonidal sinus disease revealed deep subcutaneous tracts



Figure 2. The wound was packed to allow healing by secondary intention

depressed and does not feel or act herself. Once the lesion has emerged, it may be painful but psychologically she feels more balanced.

If a lump is bad, Becky takes 500mg flucloxacillin four times daily. She also takes co-codamol 30/500mg every 6 hours to manage the pain. When lesions weep or bleed, she uses bandages to clean the area and then covers the wound with bandage and plasters.

ACCESSING TREATMENT: ADDITIONAL CHALLENGES

For the best chance of managing a flare-up, Becky needs antibiotics as soon as she feels a lump developing. This presents a logistical nightmare. The first challenge involves securing a GP appointment at short notice. This often involves Becky accepting an appointment with a GP who does not know her, who has a working knowledge of HS but lacks detailed understanding, and having to leave work early. In the next challenge, Becky has to educate the GP about her condition and explain that she needs strong antibiotics to manage it. As a result of antimicrobial resistance, GPs are very cautious about prescribing treatment and refuse to issue a repeat prescription. Becky is typically given a 7-day antibiotic regimen that she has to collect from the pharmacy, which is nearby but does not always have the prescription in stock, so she sometimes has to wait until the next day to collect it. In the final challenge, if the lump does not go away and forms a head or Becky develops a fever and feels sick within a few days of her antibiotic regimen, she needs to go straight to the hospital for further medication. Accessing medication in a timely manner is therefore very time-consuming and stressful for her.

THE WIDER IMPACT OF HS

HS has had a significant impact on Becky's quality of life. It makes her feel as though she is not in control and she often wonders when the next lesion will come up. The pain associated with the condition can affect her sleep and concentration, making work and socialising difficult at times.

The condition has affected Becky's self-confidence and relationships. As a result of the lesions, her armpits are full of scars, which make shaving and waxing difficult. Becky avoids

wearing short sleeves in the summer due to the scarring. Discharge from lesions stains clothes and can be odorous, which she finds embarrassing. She feels fortunate, however, that she has not experienced any foul-smelling lumps. HS also interferes with her sex life.

There is misunderstanding surrounding HS; in many cases, people seem to assume it is a condition related to poor hygiene. Becky finds the stigma associated with this hard to bear.

PILONIDAL SINUS DISEASE

PSD affects the natal cleft and the complications following surgery can cause more problems than the primary disease (Young, 2019), as in Becky's case. In September 2016, doctors decided that Becky needed to have surgery to remove a lump on her tail bone, which they had diagnosed as PDS. It was 12 months before Becky underwent day surgery at general hospital and at this time the extent of the disease was much greater than anticipated, with a network of deep subcutaneous tracts. The surgery was invasive and resulted in wound complications that dramatically extended the recovery period. Becky was left with a deep, painful wound (Figure 1). The cavity was packed to allow it to heal by secondary intention (Figure 2), and covered with a silver hydrofibre to reduce the risk of infection and adhesive foam to absorb exudate.

Initially, Becky's dressings needed to be changed daily with the assistance of a community nurse, but the community nurse was unavailable so Becky had to visit the hospital daily for dressing changes, adding a considerable burden on top of her existing health problems and proving very costly for the NHS. She developed an allergy to the adhesive part of the dressings, which caused her skin to become red, inflamed and itchy (Figure 3). Despite the adhesive allergy, Becky's dressings were not altered as they needed to attach to the periwound area to hold the wound packing in place. After 9 months, the wound had healed sufficiently for the adhesive dressing to be stopped (Figure 4), and Becky started using a barrier cream to protect the area.

For months after surgery, Becky was only able to move around gently. She needed considerable time off work and ended up on reduced income. In



Figure 3. Becky's skin became red, inflamed and itchy due to an allergy to the dressing adhesive



Figure 4. Becky's skin improved after the adhesive dressings were stopped and she started applying barrier cream

order to enable the wound to heal correctly, reduce the risk of further complications and to reduce discomfort, Becky was unable to lie or sleep on her back or sit up during the first 3–4 months of her recovery. Despite the discomfort she was in, financial pressures forced Becky to return to her full-time office-based role – where she was seated at a desk all day – after 2 months. The surgical wound took around 9 months to heal.

RECURRENCE OF PSD

PSD has a very high recurrence rate (Young, 2019) and Becky required another day surgery in July 2018, this time at another hospital. The second wound was slightly smaller than the first had been and was managed using the same dressings as before. Despite needing to attend the hospital for dressing changes, the journey was shorter and less stressful than the trip to the previous hospital had been. Becky's boyfriend was very supportive of her and ensured that she focused on recuperation following surgery. Her recovery took 2 months and resulted in better healing than after the initial surgery. At this time, Becky was in a new, less stressful job that enabled her to take greater care of herself, get sufficient exercise and take small breaks away from her desk as needed.

LIFESTYLE CHANGES

Becky feels that when she loses weight, lowering her body mass index, her HS improves. She exercises regularly and walks a lot, with the aim of taking 10,000 steps per day. She also has a balanced diet. Her sister, who was a smoker and perhaps suffers more as a result, was told to avoid tomatoes and other red food. Both she and Becky tried this, but it did not seem to make a difference to their symptoms.

Becky previously had a very stressful job. Financially and morally she felt compelled to return to work quickly after surgery, as she managed the office and felt her colleagues were under immense pressure without her. As a result, Becky returned to work much sooner than she would have liked and felt that the high stress levels associated with the pressures she was put under contributed to her slow recovery. She applied for her current full-time role with the aim of achieving a better work–life balance. She now

manages staff working in banks based in hospitals and is much happier. By chance, she now manages someone who also suffers from PSD, so she has been able to share her experiences and support him through her understanding of the condition. She motivates him to get up and walk around, even when he does not feel like it.

A POSITIVE FUTURE

Becky does not think that her two conditions are linked and considers their coexistence a coincidence. She thinks that she will have HS for the rest of her life but feels freed from PSD since the second successful operation, and therefore thinks of it as acute. Despite all of the hardships caused by HS and PSD, Becky maintains a very positive attitude to life, focusing on healthy lifestyle choices and taking great pride in helping others. She hopes that illustrating her journey will help other patients with these diseases and lead to a better awareness of the conditions among the healthcare staff who manage them.

CONCLUSION

Healthcare professionals need to be aware of the challenges that patients with these conditions face. Both impact an individual's lifestyle, cause pain and have a negative impact on wellbeing. Healthcare professionals can advise and support patients with lifestyle changes and provide prompt access to medication to minimise the impact of HS. Surgical treatment of PSD can be associated with delayed healing and infection, so the provision of optimal wound care is essential. Hopefully, a greater understanding of the challenges and impacts associated with these often chronic conditions will improve the support patients receive and lead to improved outcomes.

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