

Pressure Ulcer and Lower Leg Wound Care

Experiences of those affected by pressure ulcers and
lower leg wounds – July 2022

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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

1. At Healthwatch Norfolk we have five main objectives:
2. Gather your views and experiences (good and bad)
3. Pay particular attention to underrepresented groups
4. Show how we contribute to making services better
5. Contribute to better signposting of services
6. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Summary

Why and how we looked at this

Healthwatch Norfolk was commissioned by Norfolk Community Health and Care NHS Trust (NCH&C), as part of an ongoing series of focus groups, to conduct a Norfolk-wide review and explore and gather feedback on the experiences of people, as well as family or carers of people, who have or had suffered from pressure ulcers and lower leg wounds. We did this by conducting interviews with those who have suffered from pressure ulcers or lower leg wounds, their family or carers, and professionals.

Healthwatch Norfolk discussed sample size with NCH&C for one focus group of 5-12 participants. However, due to the immobility caused from pressure ulcers and lower leg wounds we were unable to host a focus group as initially planned for this project, instead electing to gather information and feedback through one-to-one interviews. Nevertheless, we were able to identify themes in the care and treatment of pressure ulcers and lower leg wounds and provide relevant quote from this small number of people.

What we found out & What this means

From the questions we asked participants we found that the main impacts on people's lives were to do with their levels of physical activity and negative impacts on their mental health. Whilst some participants felt there was no change to their wider lives, we heard how many suffered a reduction in their physical activity due to reduced mobility, for some this may have been linked with other conditions. Many participants told us how they experienced a negative impact to their mental health and well-being, often feeling depressed, worried, and stressed. Participants also spoke with us about the impacts on their relationships and independence, where one participant was providing care and treatment for their loved one who was suffering from pressure sores, which caused the partner stress and impacted their working life.

Most participants told us that they felt the Covid-19 pandemic had little-to-no

effect on their access to treatment or care for their pressure ulcers or lower leg wounds. With only one participant telling us how they experience a shortage of nursing staff at their local surgery, and the inability to access specialist clinics.

The feedback and experiences gathered by this project identified that there are poor levels of communication not only between service staff and patients but also within the services themselves. Participants expressed that they felt as if they were not being involved in their own care, and for some that important treatment and care decisions were being left to them to decide, with no information or guidance. Of those we spoke to who were receiving care through home visits many told us how service staff would consistently not show for appointments with no communication before to let them know of the change.

We also heard that participants found there to be a lack of available knowledge and information regarding pressure ulcers, their causation, and treatments provided through the services. Some told us how they felt the lack of knowledge and training also extended to those working in the services, finding their treatment and care being administered by staff who were not trained to handle pressure ulcer cases. Lack of knowledge regarding treatment for one participant led them to conduct their own research and self-treatment after various unsuccessful treatments were prescribed by professionals.

Feedback also highlighted how many participants had overall negative experiences with both the services and staff whilst receiving care and treatment for their pressure ulcers or lower leg wounds. We heard how some felt that their care was not handled in a professional manner, and how others had lost faith in the services as a result. Additionally, participants told us how various members of staff in their care acted unprofessionally and had poor attitudes towards providing care, and in some cases were rude to them as patients. The positive experiences participants had with staff were often from local nurses doing their best despite a lack of training for pressure ulcer care.

Recommendations

As a result of this feedback we have made several recommendations regarding how there could be an improvement to the treatment and care of pressure ulcers and lower leg wounds.

1. To make more knowledge available to public and staff about pressure ulcers, including but not limited to; risks, causes, and treatments.
2. To improve communication and ensure that patients feel more involved in their own care. Where treatment is concerned, when presenting patients with options strive to help guide them towards the best/most appropriate treatment for their needs.
3. To improve training of staff regarding pressure ulcer care and treatment. Ensure that a basic level of knowledge is easily accessible for staff to be able to identify, initially treat, and signpost patients to specialists for further care.

One of the limitations of this project was the small sample size, and therefore the sample is not representative of the patient population. We would encourage further engagement on a larger scale for further projects and research concerning pressure ulcers and lower leg wounds.

Why we looked at this

Pressure ulcers, also known as pressure sores or bedsores, (NHS, 2020) can occur in anyone in the population, however there are some who are more at risk of getting them than others. For example, those who are less mobile, such as those confined to a bed or wheelchair for long periods of time (NHS, 2020), or those who are seriously ill. They can affect any part of the body but are most common on bony areas, such as heels and hips, and are primarily caused by prolonged pressure on the skin (NHS, 2020). Over 700,000 patients are affected by pressure ulcers, with 180,000 being newly acquired, each year in the UK (Wood *et al.*, 2019).

Older people are more likely to develop pressure ulcers, however age alone is not a risk factor but the problems more common in older age that are associated with the development of pressure ulcers such as, hip fractures, faecal and urinary incontinence, smoking, dry skin, chronic conditions, or terminal illness (Public Health England, 2015). Pressure ulcers can lead to longer stays in hospital which in-turn can result in increased mortality, morbidity, and a reduced quality of life (Wood *et al.*, 2019).

Pressure ulcers continue to remain a concerning and mainly avoidable injury related to healthcare delivery (NHS Improvement, 2018), as well as remaining a concern and challenge for the patients who develop them and the health professionals that support the patients in prevention and management (Stephenson *et al.*, 2021). Pressure ulcers also represent a considerable financial cost to the NHS, where in 2015 the estimated cost per pressure ulcer was between £1,214 – £14,108 based on severity (Wood *et al.*, 2019).

Treatment for pressure ulcers is dependent on the severity of the wound, ranging from basic nursing care to more serious treatment to avoid life threatening complications (NHS, 2020). Wood *et al.* (2019) note that, despite the available knowledge for prevention of pressure ulcers and guidance from The National Institute for Health and Care Excellence (NICE), the Institute for Healthcare Improvement (IHI), and the Surface, Skin inspection, Keep your patients moving, Incontinence/moisture, Nutrition/hydration (SSKIN), the clear prevalence of these wounds being nationally reported is indicative that good pressure ulcer care is not consistently embedded into nursing practice.

Healthwatch Norfolk was commissioned by Norfolk Community Health and Care NHS Trust (NCH&C) to look at health care services across Norfolk, and to engage with people, as well as family and carers of people, who have been affected by pressure

ulcers and lower leg wounds, to provide insight into the treatment, care, and prevention of pressure ulcers in Norfolk.

Healthwatch Norfolk designed a guided discussion for a focus group to find out more about the experiences of people, family, or carers, who have or had suffered from pressure ulcers or lower leg wounds.

We wanted to know:

- If people knew where and how to seek help and advice concerning their pressure ulcer, and who they went to.
- If they felt they sought appropriate support at the right time, or if there were barriers to accessing treatment.
- Public knowledge of pressure ulcers prior to developing them.
- If their pressure ulcer or lower leg wound impacted their:
 - Relationships
 - Independence
 - Wellbeing
 - Physical Activity
 - Employment
- If the COVID-19 Pandemic affected their experiences.
- What would have made living with a pressure ulcer/ lower leg wound better.
- Had there been anything that had made a difference to their experience.

The feedback received helped us to identify themes related to peoples, families, and carers experiences of pressure ulcers and lower leg wounds and make recommendations for learning and improvement of services.

The feedback of these interviews is evaluated in section 3 of this report.

How we did this

Methodology

The project aimed to explore the experiences of people who have, or have recently had, pressure ulcers or lower leg wounds; or people who are family members and/or carers for people affected by pressure ulcers or lower leg wounds. Feedback was gathered via one-to-one interviews. The area of focus for this report was selected by partners at NCH&C as part of a larger, on-going, programme of focus groups.

The target audience of this project are Norfolk residents with pressure ulcers, or lower leg wounds, as well as their families and/or carers. As NCH&C provides support at various sites across the county, to a large patient base we cannot say that the sample size of this report is representative of the patient population. However, it is a snapshot which can be used to support future work.

Healthwatch Norfolk discussed sample size with NCH&C for one focus group of 5-12 participants. However due to the immobility caused from pressure ulcers and lower leg wounds we were unable to host a focus group as initially planned for this project, instead electing to gather information and feedback through one-to-one interviews. Nevertheless, we were able to identify problem areas in the care and treatment of pressure ulcers and lower leg wounds and provide relevant quote from this small number of people.

To encourage participation, Healthwatch Norfolk developed promotional materials which were then distributed through Healthwatch Norfolk's well-established network with a goal of reaching as many individuals, and groups, as possible, including those seldom heard. Healthwatch Norfolk will promote the project by means of posters in specialist clinics and surgeries, as well as using social media posts, a dedicated webpage on the Healthwatch Norfolk website, and in the Healthwatch Norfolk newsletter.

Additionally, Healthwatch Norfolk engaged with NCH&C staff and other service staff to canvass and gather the opinions of professionals working with pressure ulcers and lower leg wounds on a regular basis.

Over the course of this project, it was discovered that, due to the sometimes-sensitive nature of pressure ulcers and lower leg wounds and the immobility that these can cause for individuals, a focus group would be inappropriate for gathering feedback. Therefore, the methodology for gathering feedback, for this focus area, was adapted and adjusted from a focus group to one-to-one interviews.

In total 7 individuals were interviewed via telephone conversation, and 1 participant answered questions independently. The Group consisted of those suffering from pressure ulcers, their partners, and a carer from a residential care home.

Participant Involvement and Consent

Participation in interviews was voluntary, with participants approaching Healthwatch Norfolk to share their experiences. Participants had to give their consent for their answers and feedback to be shared in this report anonymously.

Interview Data Analysis

Interview transcripts were analysed using thematic analysis in NViVO and the themes are reported in section 3. A copy of the interview questions can be found as Appendix 1.

What we found out

Wider Impacts

We asked participants if their experiences of suffering from a pressure ulcer impacted various aspects of their wider life including their relationships & independence, their wellbeing, their ability to work, and their levels of physical activity.

Of those we spoke with, several told us about a decrease in their mobility and one participant told us how suffering from their leg ulcer and being on their feet all day makes them *“dead tired”*. Another participant explained to us that their *“ulcer is just below [their] ankle joint and affects the bottom of [their] foot. So, when [they] put [their] foot down, it’s like standing on a bed of nettles. So, it’s soreness as well as difficulty”*.

Some participants felt that their pressure ulcers did not impact their levels of physical activity. One participant told us that because their partner looked after and treated their pressure sores there hadn’t been an affect on their physical activity; *“So in real terms, it hasn’t had an effect because I’ve had someone look after me. But it would have had an effect if I hadn’t.”*

One participant we spoke to felt that their levels of physical activity had been impacted, but more so by other conditions rather than their pressure ulcer.

“That’s not the ulcer, really, that’s stopped me from doing things. I think it’s just the arthritis more.”

Some participants told us that they felt their relationships had been impacted due to the added mobility problems, one said that *“[they] can’t walk to a health centre, [they] can’t get to my church”*, meaning that they were not able to socialise as much. The care professional we spoke with also told us how during the Covid-19 pandemic, when lockdown was in effect, residents *“Families didn’t visit”* and *“some isolated in rooms.”*

One of the participants we spoke to told us how, over time, communication with friends had deteriorated; *“it’s not easy because all my friends are quite elderly, a*

lot of them are, and the others are all working". Whereas another spoke to us about how their phone conversations with friends increased, but in person meetings decreased partly due to the Covid-19 pandemic.

Personal stories:



"And I still keep in touch with all of St. John's- the retirement fellowship. The retired members. Because they're all getting elderly now. And some of them are even older than I am. So, I do like to ring them, just to make sure they're all right and just have a little chat with them because they can't get out either. So, I do feel as though we're still doing our little bit by ringing them. And I mean, up until COVID, I was meeting them once a month. We were all getting together once a month and taking them out for a meal. And they really look forward to that, going out once a month for a meal. But since COVID, we just haven't really done that."



– Person suffering from pressure ulcers.

We asked participants if they felt that their mental health and wellbeing had been impacted by their pressure ulcers or lower leg wounds. Most we spoke to felt that there had been, saying how "it gets [them] down a little bit", "it just gets [them] depressed", and that "it's a stressful time". The carer we spoke with told us that, for residents, it *"affects wellbeing as loss of independence restricts social activities & physical activities."*

Some we spoke to felt that their mental health wasn't affected. One participant said, despite feeling *"that [they're] withering away here"*, they didn't *"think so because I'm a very positive person. And I have, you know, an enjoyable life, and the promise of other life and I'm quite happy, you know, I don't get miserable, I always have plenty to do."* Another participant told us; *"It obviously makes you fed up because sometimes it is there for a long period of time, and you think, well, is this ever going to get better but no, I wouldn't say it's affecting my mental health."*

Most who we spoke with were no longer in employment so there was little impact

to their working life. One participant told us how they had no impact on their work at all. Whereas, another told us how they were carrying on as normal, with no changes having been made by their employer, but would feel more tired than usual at the end of their day due to *“walking round all day on feet and leg, and the swelling the leg cause[s] like, uh, [their leg] to get heavy”*.

We spoke to the partner of someone who had developed pressure ulcer, who told us how their work had been impacted due to need to support and care for their partner. They told us that *“even though [they] only work very part-time, [they've] had to take time out of work and make the time up other times to take [their partner] various places.”*

Additionally, we asked participants if they felt that the Covid-19 pandemic had affected their experiences of receiving care and treatment for their pressure ulcers. Most we spoke to told us that the pandemic did not have much of an impact for them, *“Apart from wearing mask of course”,* finding that appointments mostly remained the same or moved to online where possible.

One participant we spoke with told us that Covid-19 had impacted various aspects of their life, telling us that impacts to their well-being was *“to do with COVID, really, because [they've] not been able to go out.”* They also told us how the pandemic affected their ability to access care and treatment for their pressure ulcer, telling us how they have experienced a shortage of nursing staff and being unable to go to a specialist centre; *“I rang them up and they said that I couldn't go up there because of COVID, so I wasn't able to go there anyway.”*

“There's been times when nurses couldn't come because they just haven't had enough nurses. They've been so short of nurses, they've been desperate, they've told us this and you do feel sorry for them because it's not their fault”

Due to the demographic of those we spoke with, it is difficult to accurately determine the impact of pressure ulcers and lower leg wounds on wider life as most we spoke to suffered from additional conditions. One participant told us that they had previously had *“a very seriously injured leg having to wear a 3 inch raise on the shoe and lots of metal in it”*. Another participant told us they thought that their ulcer could have been cause by another condition; *“[The patient] had cellulitis as well, which didn't help, of course. And the cellulitis might have caused the ulcer.”*

Poor Communication

One of the issues that we heard about from participants was around the communication between health care professionals and the patients. Participants felt that the communication about their care, needs, and treatment was poor with some feeling like they were not involved with their own care. After a visit to the hospital for an operation, which resulted in the patient leaving with pressure ulcers, one patient told us, regarding the care they received, *“It was treated like it was nothing to do with me, really.”*

Those we spoke to said that they consistently were not informed of changes to their treatment or care. They reported that nurses *“just didn’t turn up”* to scheduled visits and that they had not been informed that the visit would not be going ahead.

Personal stories:



“Within the last 6 months the continuity for instance has been a bit poor. For instance, a senior nurse, I think she was called a matron, she visited some months ago, um, for a home assessment. And she suggested, because I’ve got quite good memory, that I should dress the ulcer every other day, and then a district nurse would also visit weekly to check my progress and redress the wound and that seemed fine. But it never happened. It did not happen. It must have been discussed in other quarters and cancelled. I wasn’t told.”



– Pressure ulcer patient from Norfolk

We heard from one individual who, on several occasions, received conflicting messages from various healthcare professionals around the best treatment for their pressure ulcer. *“A year later, when I got the ulcer on the other leg I said to my GP, who shall be nameless, I said ‘Do you think I could have the injection the consultant suggested into this leg because it’s going to ulcerate?’ and he said, ‘That won’t help you at all’. No appointment made, no referral, so I just sort of had to get on with it you know.”*

Another participant felt there was a distinct lack of communication of information for pressure ulcers, and the potential risk of developing them when visiting hospitals for other procedures.

“It’s just a lack of information, really. When you go into hospital, like anything, you should have things explained to you.”

Participants also felt that the communication within and between the services was poor, feeling that messages were not getting reported on their notes, or being shared with other staff. One told us about how they had to make a complaint about a rude member of staff, only then for an appointment to be offered with that same member of staff on a separate visit, *“Even though you make a verbal complaint, it doesn’t seem to – you’d think it’d be on your notes, wouldn’t you?”*

Lack of Knowledge Available

For those we spoke to, some knew where to seek help and advice due to having previously suffered from pressure ulcers, lower leg wounds, or other conditions that affect their legs. Those who we spoke to who had no prior knowledge of pressure ulcers told us that they went to their local GP; *“I went to my local doctor surgery to see a nurse I know there, but there’s no, there were no like leg ulcer clinics at the time when I was going to nurses”*

One participant, who developed pressure ulcers during a visit to hospital for an operation, had a partner who had knowledge of pressure ulcers but told us that *“if [they were] on [their] own [they’d] probably phone the doctor”*.

Most participants felt that they sought help and advice at the right time, telling us that when they felt that something was wrong, they contacted either their GP surgery or a specialist clinic. Additionally, those who had previously suffered from pressure ulcers knew what early warning signs to look out for; *“I know when I’ve got an ulcer because I’ve had them before. [...] they throb, they throb actually. You get a throbbing feeling and it’s uncomfortable.”*

Only one participant told us that they thought they *“could have gone a little bit earlier”* but that *“[they didn’t] know that that would have made any difference to the eventual outcome.”*

Participants felt that there was a distinct lack of knowledge, regarding pressure ulcers, available to the public. Of the people we spoke to only those with professional experience, or those who had suffered from pressure ulcers before, had some knowledge of the condition.

“I think this whole thing is based on knowledge. [...] I have no knowledge of what a pressure sore is, what it feels like, what it looks like, anything like this.”

One participant told us that they were unaware that pressure ulcers can affect anyone of any age saying, *“I’m a young person and you just don’t expect these things to happen.”* They developed pressures sores after a short period lying in bed however, their understanding was that *“pressure sores are things that people in comas have who are laying down for 6, 7 months.”*

Of those we spoke with only those who had suffered from pressure ulcers before or had a family member/ carer with knowledge of the services available knew that there are specialist clinics that can be contacted for care. Most participants would seek care from their general practice.

We spoke to a family member, of someone suffering from pressure ulcers, who had knowledge of the condition as well as professional experience working in the services. They told us how, without their support, their partner would be in a much worse situation.

Personal stories:



“So, you asked my husband if he knew where to seek advice. He didn't at all. We went to see the practice nurse. And if I wasn't involved with him, I mean, A, he wouldn't have gone to the practice nurse at all because he wouldn't have known it was there. But if he had managed to get himself to the practice nurse, he'd have just been seen by somebody who isn't experienced in pressure ulcers, probably wouldn't have identified it as one, dressed it as a normal



wound which is what she did. So, he had no idea”

– Family member of patient suffering from pressure ulcers.

Participants also felt that knowledge of pressure ulcers was also lacking among healthcare professionals. One told us it seemed *“that so many people have so many different ideas about recurrence of ulcers, causation of ulcers, treatment of ulcers”* and that they had received various treatments from different professionals.

A few of the people we spoke to told us that nurses looking after their care had not been trained to handle pressure ulcers, *“we thought they were ulcer nurses, but they actually said they hadn't really done any training for ulcers”*. One told us how their nurse mistook a pressure ulcer for a blister, and so they believed that it was not correctly reported.

As older people are more at risk of pressure ulcers, due to reduced mobility, one participant we spoke with told us that they would like to see more general information and knowledge being given about growing old.

“I'll tell you what I would like to see, from the health education point of view. Somebody's always telling a pregnant woman what it's like, you know, to deliver, and what it's like to feed a baby, and this. Or somebody with mental issues, perhaps we can get together to talk about, this, this, this, you know, here's a number, you know. Nobody tells anybody, with any sense, about what it's like being old.”

Self-treatment

Treatment of pressure ulcers and lower leg wounds varied for participants, and several participants reported that they had various treatments over a number of years. One participant told us that they *“could name, over the last 2 years, at least 10 lots of different treatments that have been tried.”*

Whilst a couple of participants reported that they *“received good treatment”* from nurses and that *“they did their best, but they're not trained in ulcers.”* Most who we

spoke to reported dissatisfaction with the treatment they had received, with those receiving various treatments feeling that *"none of them really seemed to work"*.

Speaking with participants who had support from family members, they felt that had it not been for the support their treatment would have been far worse. When asked if their pressure ulcers impacted their physical activity levels; one participant told us *"the pressure sores and everything have been looked after, dressed, cleaned, everything like that from [partner] [...] So in real terms, it hasn't had an effect because I've had someone look after me. But it would have had an effect if I hadn't."*

Speaking with the family member; they told us how they had to advocate for correct treatment and care support for their partner, and how it has impacted their own work and life.

Personal stories:



"I've had, as you know, shed loads of work to do on this in terms of caring for him and advocating for him. None of these things would have happened if it wasn't for me. None of them. And just the stress of having to fight for it and insist on stuff. You shouldn't have to insist on anything."

– Family member of patient suffering from pressure ulcers.



An issue for patients who relied on the services for their treatment was a lack of consistency, despite being told *"You mustn't dress this yourself, you mustn't, we must come"* one participant told us, *"Well they don't come, and sometimes you have to renew a dressing"*.

Another participant was told nurses would *"bring the hosiery to [them] because obviously, they wanted to see if I [the patient] could get it on. There's one nurse who said, "I don't think for one minute you're going to get them on anyway."*, they said that they have *"been waiting and nobody's been, and [they] began to think, well perhaps they're not going to bother."*

We found that a number of participants were having to self-treat their pressure ulcers and lower leg wounds due to nurses not arriving for visits to administer treatment, one

participant told us they *“had to place [their] ulcerated leg in a plastic carrier bag to preserve my bed clothes, and mattress, from severe watery leakage.”*

We spoke to one person who, due to various unsuccessful treatments, had chosen to stop receiving care from their GP and conducted their own research and treatment of their pressure ulcer with some success. The participant was able to do this through online research for their condition and similar conditions, this, however, would have been more difficult if the participant had limited access to the internet or was less computer proficient. Another reported that their condition *“seems to have almost cleared up”* as they had *“been looking after her leg”* despite *“no nurse [coming] in for about three weeks”*.

Personal stories:



“Eventually, I just did some various bits of research on my own. And I found out that people who had this-- had a similar condition used to put oatmeal in the bath. [...] I did notice that there was a cream called Aveeno, and I've been using that for the past - I don't know - three years or so. And that's the only cream that I've ever used which has ever had any impact on it, and it basically contains an extract of oatmeal, and that seems to keep things under control now.”

– Self-treating pressure ulcer patient.



Services Handling of Pressure Ulcers and Lower Leg Wounds

Most of the people we spoke to, overall, had negative experiences with the services regarding the treatment and care of their pressure ulcers or lower leg wounds. One participant felt their experiences with the services were generally good, with only one issue where they felt they were unable to get an emergency appointment *“because [they] had an appointment later on in week.”*

Some of the other participants reported that they had some good experiences in their treatment and care, one told us how helpful the ambulance staff were in getting them

to their appointment; *"The ambulance man, he'll say 'well, can you manage these steps?' and I'll say, 'well yeah really... I'll have to throw my leg up', 'oh no, no, no, no, no, I'm putting down the ramp'. And I think, oh that's lovely really, they bother about you, they don't always take the easiest way you know".* Another told us that *"When [nurses] were able to come, they did come in"* and that they were *"just pleased to see somebody."*

Personal stories:

We also spoke to a member of care staff who takes care of residents in a care home. They told us about the extra work staff were now putting in.

- *"As a carer, we do not dress ulcers. But on occasion, and in best interest, we have had to."*
- *"Wet dressings will smell, cause more problems, residents have removed dressings as district nurse not come as often as needed."*

Many of the participants were dissatisfied with the services that they, or their family members, received. One participant told us how they felt that they weren't being involved in their own care, *"who knows what to do, how do they decide what to do, how'd they tell people what's happening, and what encouragement do they give you? Pathetic really."*

Some participants told us how they have lost faith in the services as a result of their care and treatment. *"We've just lost faith in a lot of them now [...] you'll hear people say, 'Oh, that's how things are. That's the times we're living in.'" But it's just not good enough really, is it?"*

"So, I stopped going to my GP because none of the creams that he prescribed had any great effects. And then the same with the hospital. They didn't really know what the condition was, except to describe it as perhaps psoriasis-related condition."

One participant told us how they would feel happier in a residential care setting, offered through social services, having *"someone there in the building when [they're] not very well"* would be better, saying that *"at least [they] can call on someone or have care if [they] need it."* When asked, what they thought made a difference for their resident's

care, the member of care staff we spoke to told us that their *“residents were lucky they had carers around them for support throughout. Mentally and physically.”*

One of the issues with the services that we identified, from speaking to participants, was that there was a general feeling that they were not doing all that they could to provide the best care and support for those suffering from pressure ulcers and lower leg wounds. One participant told us how they felt that *“You’re signed off too quickly as well. As soon as, you know, a minimal healing of skin that’s it no more appointments. And then it comes back again, this is what happens again and again.”*

Other participants told us how they felt that their care was being ‘passed off’, feeling that nurses *“concentrate on their task, you know, i.e., dressing the ulcer.”* Rather than understanding the patients’ problems. One told us how they regretted mentioning their experience working in the services, *“I’d made a mistake of saying I’d done St John because as soon as I said that they more or less say, ‘Well, really, you’d be probably better off to do it yourself.’”*

One participant, who developed pressure sores whilst recovering from surgery, told us *“it also makes me feel a bit like that I went into hospital and wasn’t treated in a professional way that I would expect”*. When asked how the pressure sores had affected various aspects of their life, relationships, independence, and wellbeing. They told us; *“it’s hard enough having the hip surgery and getting back to walking and trying to-- all that kind of stuff without having to worry about what’s on the back of my legs.”*

Personal stories:



“So, in some ways, it has-- yeah, I mean, it had a big effect because it’s something that you don’t expect that when you come back from hospital, you’ll be kind of in a worse position than you went into the hospital, I mean, obviously apart from the hip replacement.”

– Patient suffering from pressure ulcers.



Staff Attitudes

Many of those we spoke to told us how their experiences with staff were often poor and for some participants how staff were rude in their behaviour and attitude. One participant told us how “some of them are a bit abrupt. Apt to say things which are not appropriate”. Another participant and their family member spoke to us about how one nurse “was so rude” to them that they made a formal verbal complaint. We also heard from a partner who was now providing care how, when they returned to the hospital to address the pressure sores they developed whilst originally there, specialist nurses “[spoke] to [the patient] like [they’re] demented and [they’re] deaf.”

One participant told us how they felt that they were not a priority to staff and that there is a general issue with staff behaviour; “I think there’s a problem with general behaviour towards people, particularly older people.”

Personal stories:



“Because every time we saw her, she seemed to stand behind the cupboard door and close the door so we couldn't see her face and then she'd say all sorts of awful things to us about, "Oh, well, you're obviously not doing the right thing" or "You should be sitting with your foot up." She said all sorts of things [...] it was no good trying to speak to her because she just didn't listen to anything we said.”



– Person suffering from pressure ulcers.

Participants also told us about how staff acted unprofessionally in their treatment of patients. One told us how, regularly, on visits to the clinic they would be told by staff “*Well, I've seen people with wounds that are much worse than yours*” and how they felt that “*it's not a very useful or kind approach really.*”

Another participant shared with us how a nurse refused to let them see a doctor when they requested to. “*She wouldn't let me see a doctor. I said, "I really think a doctor ought to just have a look." And I was on antibiotics for cellulitis, so she said, "You don't need antibiotics and you certainly don't need to see a doctor." That was her very words. And I*

said, "Well I think really I would feel happier if I could just see a doctor." But she wouldn't let us see a doctor."

The partner, of someone who developed pressure sores whilst recovering in hospital, told us about their experience. They spoke to us about how specialist nurses touched various surfaces whilst wearing PPE, and *"the head of tissue viability [...] touches the orange surgical waste bin with her gloved hand"* right before going to examine the patient, and how the partner had to stop them. They also told us how the other specialist nurse lied in *"an out and out effort on her part to divert me from the known fact that they had caused an avoidable pressure ulcer."*

"We accede to the authority that medical practitioners have because we think, A, they're going to act in our best interests. They know best for us. And they know best that they're doing good practice. So, we just trust them, don't we?"

Some participants told us about their good experiences with staff during their treatment and care. One spoke to us about how staff at the ulcer clinic were *"very caring, friendly, do their best"* and another told us how, after informing the clinic that they wouldn't be able to physically go to collect medication for an appointment, a *"very kind nurse phoned, and she said, she'd picked up my message and she dealt with the problem, she understood, she was very good."*

Other participants told us how the staff they saw *"did their best, but they're not trained in ulcers"*. One felt *"I thought I was looked after very well by the untrained staff. But they sometimes seem to be doing jobs that should be done by trained nurses."* Participants felt that whilst there were some supportive staff, what they felt was they *"needed somebody to be able to tell me who knew what they were doing."*

"And the nurses there used to say to me-- They used to say, "Should we try putting some silver on? Should we try putting this on?" And honestly, I thought, "Well, you're the nurses. You should be telling me what you should do." And I said, "Well, I really don't know," I said, "You do what you think is best, what you know you should do."

What this means

The findings of this study were collected from a small sample of participants, mostly due to the nature of pressure ulcers and lower leg wounds as well as the typical demographic associated with these. Demographically, pressure ulcers are more typical in older people and those who have mobility problems. We spoke to one participant who was of a younger age, this highlighted the lack of knowledge available about pressure ulcers and how they can develop at any age.

Participants told us how their experiences with pressure ulcers or lower leg wounds had impacted their lives, with the main impacts being a decline in levels of physical activity and a negative impact to mental health and well-being. However, some participants told us that they did not feel or see an impact to these areas of their lives. When we asked participants if the Covid-19 pandemic had affected their access to care and treatment, most told us that they saw little-to-no impact, with appointments either continuing in person wearing masks, or changing to virtual appointments. One participant told us that they experienced an impact as their surgery suffered a shortage of nurses and specialist clinics were unable to see them.

It is important to note that due to the typical demographic of those suffering from pressure ulcers, it is difficult to accurately report on the wider impacts to lives as many those suffering from pressure ulcers and lower leg wounds may also be suffering from other conditions.

Of the participants that we spoke to, most had an overall negative experience with receiving treatment and care of their pressure ulcers/ sores and lower leg wounds. We also spoke to a member of staff at a residential care home who spoke with us about the additional care they had to provide due to reduced visits from other professionals.

The issue most participants felt they encountered with their treatment and care was the poor levels of communication between the professionals and themselves, and between/ within the services. They felt that, often, they were not informed of changes to their treatment, visits, and care, and that there was a general lack of communication regarding information on pressure ulcers.

Many who we spoke with felt that they were not being fully involved in their own care, whereas some felt that they were being asked to make important decisions with no information or guidance from the professionals who should know what is best.

One of the general concerns that came from this piece of work was that there appears to be a lack of information and knowledge available to the public regarding pressure ulcers including, but not limited to, causation and treatment. Additionally, participants felt there was a lack of knowledge and training in the services for the best treatment and regular care of pressure ulcers.

One participant we spoke to, told us how they conducted their own research and found an alternative remedy due to numerous failed treatments from their GP and hospital visits.

A number of those we spoke to found themselves having to administer treatments themselves or having family members care for them, due to nurses consistently not arriving for visits and appointments.

Participants had some positive experiences with their treatment, mainly from local nursing staff who did their best to aid patients despite a lack of training in how to handle pressure ulcer cases.

Due to the immobility caused from pressure ulcers and lower leg wounds we were unable to host a focus group as initially planned for this project, instead electing to gather information and feedback through one-to-one interviews which resulted in a small sample size. Despite this, the work reported on here highlights some of the issues in the care of pressure ulcers and lower leg wounds and could provide a starting point for a potentially larger explorative project.

Recommendations

From the findings of this piece of work several recommendations can be made for Norfolk Community Health and Care NHS Trust regarding how to improve the treatment and care of pressure ulcers and lower leg wounds.

1. To make more knowledge available to public and staff about pressure ulcers. Including but not limited to; risks, causes, and treatments.
2. To improve communication and ensure that patients feel more involved in their own care. Where treatment is concerned, when presenting patients with options strive to help guide them towards the best/most appropriate treatment for their needs.
3. To improve training of staff regarding pressure ulcer care and treatment. Ensure that a basic level of knowledge is easily accessible for staff to be able to identify, initially treat, and signpost patients to specialists for further care.

Due to the small sample size for this project, and the sometimes-sensitive nature of pressure ulcers, it has been difficult to gather a representative sample of patients. We would encourage further engagement on a larger scale for further projects and research concerning pressure ulcers and lower leg wounds.

Formal Response

We received an official response to this report from Carolyn Fowler, Director of Nursing and Quality response on behalf of Norfolk Community Health and Care NHS Trust.

“Norfolk Community Health and Care NHS Trust have committed to a series of focus group to explore patients experiences of living with health conditions across Norfolk. I would like to thank Healthwatch for leading and facilitating the focus groups and for providing this report and recommendations for consideration. I would also like to thank the patients and carers who took the time to share their stories, without their feedback we cannot truly understand where the challenges are of living with health conditions and what our role needs to be in response. The first of the focus groups looked at lower leg wounds and pressure ulcers with the aim to explore the impact of living with these conditions on individuals and carers.

The recruitment into lower leg wound and pressure ulcer focus groups was not able to be undertaken, and as a result individual experience interviews were sought. This in itself reflects the challenges of connecting with patients whose condition can restrict them in their everyday lives. Whilst we only heard a small number of peoples experiences these voices have enabled the Trust to have greater understanding of living with a leg wound or pressure ulcer and how we can explore where we need to improve or deliver services differently in the future. We will share these findings with our partner organisations to learn and improve together our patients experiences and outcomes.

Norfolk Community Health and Care NHS Trust are taking forward the lead for Healthcare Acquired Pressure Ulcers across the Integrated Care System. The aim being to join up all those involved in patient care to learn and improve as a system. The recommendations from this report will be part of ongoing programmes of work that we are committed to deliver.”

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Appendix

1.

Focus Group Discussion Guide

Project: NCH&C Focus Groups (Facilitated by HWN)

Question	Notes	Complete
<p>Welcome and start recording</p> <p>Introductions (all attendees)</p>	<p>Confirm attendees are happy for session to be recorded for transcription purposes. Recording will be deleted once the write up is complete and any direct quotes will be anonymised.</p> <p>‘Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people’s views of health and social care services in the county and make sure they are heard by the people in charge. Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more. We also give out information about the health and care services available in Norfolk and direct people to someone who can help.’</p>	
<p>Purpose of focus group</p>	<p>Healthwatch Norfolk are exploring people’s views and experiences as patients and carers of patients with pressure ulcers and lower leg wounds.</p> <p>We want to spend some time speaking to a small group of patients/carers in Norfolk. For the purposes of this discussion you should currently have a pressure ulcer or lower leg wound or have had one that has healed in the last year. A lower leg wound is a wound that you’ve had for longer than 3 months. We also welcome views from anyone who has been supporting someone with a pressure ulcer or lower leg wound, this may be a friend, relative or carer.</p> <p>This session will run for up to 2 hours to explore people’s experiences of living with a pressure ulcer or lower leg wound and the impact that it may have had on other parts of your life. We want to hear what it has been like accessing services yourself and for the person you care for, the impacts it might have had on your wider life including your relationships, your home environment and maybe your job as well as</p>	

	<p>the impacts of COVID-19. We'd like to hear what has been positive and where you would like to see improvements or changes.</p> <p>There are no right or wrong answers at this session, we are just really interested in hearing peoples' personal experiences and opinions.</p> <p>The information we take away from the discussion can be anonymised and will be used in a report to be given to service providers so they can find out what is working well and .</p> <p>We ask that attendees share with us what they feel happy and comfortable doing so and respect the privacy of other attendees by treating information confidentially.</p>	
Any Questions?		
Focus Group Discussion		
<p>Thinking about when you first realised something was wrong, did you know where and how to seek help and advice? Who did you go to?</p> <p>Do you think you sought help at the right time? (If not why not?/barriers to accessing treatment)</p>	(patient/carer perspective)	
Did you know about pressure ulcers/lower leg wounds before?/what to look out for		
<p>Did your pressure ulcer/lower leg wound have an impact on your/their:</p> <p>-relationships</p> <p>-independence</p>		

-wellbeing -physical activity -employment (<i>if applicable</i>)		
Do you think COVID-19 has had an impact on your/their general experiences of a pressure ulcer/lower leg wound?	e.g. access to treatment, advice, support from people around you	
What would have made living with a pressure ulcer/lower leg wound better?		
Can you could give an example of just one thing that has made a difference to you/them?		
Focus Group wrap up and conclusion		
Additional Feedback	Do any attendees wish to share any other experiences/views before the end of the session?	
Summary of themes	Feedback themes to group	
Thank you	Thank you to attendees and staff	



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