healthwatch Suffolk

Stoma care in Suffolk

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Background

Between July and September 2022, we asked people about their experiences of stoma care in Suffolk. This slide deck has been created for the Suffolk and North East Essex Integrated Care System to shape and influence local stoma care.

- People of all ages live with a stoma, and stoma surgery is an option available to people with various conditions (e.g., cancer, diverticulitis, and Crohn's disease).
- Our survey asked people in Suffolk, including Waveney, about their experience before the operation, and also about their experience of living with a stoma.
- The survey asked what was good, and what could be improved about their treatment and support.
- A report will also be made available to Waveney Primary Care Networks. See our website (www.healthwatchsuffolk.co.uk/ourresearch) for more details, and to access more of our research and reports.

More than **200,000** people are living with a stoma in the UK.

This report explores the responses of **31 people** living in Suffolk.

Who took part?

Location	Respondents
Babergh	*2*
East Suffolk	*7*
Ipswich	*4*
Mid Suffolk	*4*
West Suffolk	*9*
Waveney	*4*
No locality indicated	*1*
Total	***31***

31 responses were recorded from people living in Suffolk.

- Not all respondents answered all questions in our survey, and some answers included several different examples about the support people received.
- Therefore the number of responses detailed in this report may not correspond to the original number of respondents

How long have you had your stoma?

- Most had their stoma for over three years (68%).
- The respondent with over 46 years of living with stoma had a stoma as a child of 5 years.
- 32% had a stoma for under 3 years.

How long have you had your stoma	Number of Respondents
Under 6 months	*2*
6 – 12 months	*4*
More than a year	*4*
More than three years	*18*
More than seven years	*1*
11 years	*1*
46 years	*1*
Total	***31***

Most people (**68%**) had been living with their stoma for **more than three years**.

Support (before operation) – East and West Suffolk

We asked people about the support they had been offered prior to their stoma operation. 22% of the respondents did not answer this question.

Of those in East and West Suffolk who answered :

- **30%** received no detailed information. Their care had been treated as a medical emergency for various reasons.
- **25%** received excellent support and information from the stoma teams.
- **23%** received insufficient support, with too little information to satisfy their individual needs.

Support	Respondents
The stoma nurse called, or visited, explained and gave support.	*5(18%)*
Saw a consultant and nursing team who gave lots of information and support.	*2 (7%)*
Some good information about the operation, and products, but no information about support organisations.	*1 (4%)*
Support and information was not enough to give confidence.	*3 (11%)*
Received advice, but did not follow this. This led to needing an operation.	*1 (4%)*
Poor until transferred to a different hospital, then improved.	*1 (4%)*
None, it was an emergency operation.	*8 (30%)*

Support (before operation) - Waveney

In Waveney when we asked people about the support they had been offered prior to their stoma operation responses were very positive

- All four respondents said stoma nurses had visited and/or called them to discuss the operation.
- All four had received information about the operation, and the care they would receive.
- Two respondents had received information about groups and support available to them.
- One respondent stated that the care they received from stoma nurses had continued throughout the COVID pandemic.

“I was seen before my surgery and the stoma nurse I saw was at the hospital. She was great and explained what would happen. On the ward I saw her again and her team - and I was shown lots of bags and found one I liked and was seen at home by stoma nurses again.

“I was given lots of information about groups and support but I don’t need any of that. I just call my stoma nurses, and they help me. One time I needed help and the sister sent someone out on the same day. I was so grateful that I could see someone as it was when that virus stopped things but my stoma nurses never stopped.”

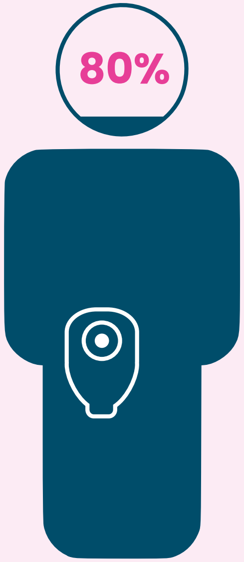
Support (after operation) – All Suffolk

We asked about support offered after the stoma operation. Of the respondents who did answer this question:

- **80%** received good or sufficient support from stoma teams and nurses (**51%** in east and west Suffolk).
- **15%** had not received any support (due to COVID-19), even if support was available before the pandemic.
- **5%** had good support before the operation, but little had been offered after the procedure.

Where there was a mixed response comments included:

- One person felt lack of support from medical staff had affected their mental health, but nurses were supportive.
- One person said the hospital had been 'excellent', but their GP had been 'horrendous'.
- Another person felt medical support was positive, but advice they had received about issues such as body image, exercise or clothing had not been helpful.



80% had **received good support from stoma teams** and clinical staff.

Support (after operation) - Waveney

Three of the four respondents in Waveney answered this question. Their responses confirmed:

- They had received good care and support following their operation.
- Two people commented that follow up visits were ongoing.
- Two people commented that they had been able to try different appliances.

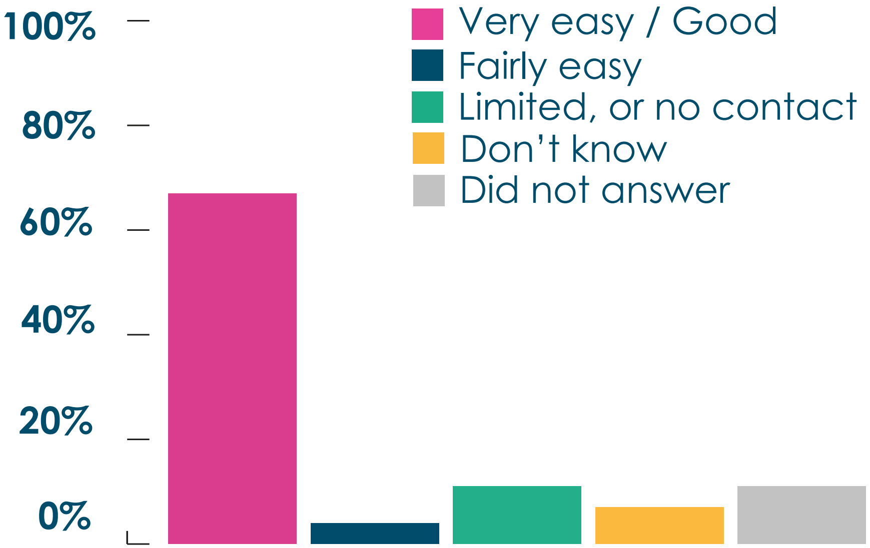
> *"Stoma nurse visited regularly. Tried different appliances.*
> *Six monthly formal review."*

> *"Yes, follow up with a telephone call and home visit."*

> *"I got lots of information, but didn't need it. I still get seen by stoma nurses even now."*

Contact (after operation)

Most (**71%**) people knew how to contact the stoma nurse if they needed help.



We asked people if, following discharge, they knew how to contact the stoma nurse if they needed help or support.

- **71%** of respondents had no problems, or found it fairly easy to contact the stoma nurse.
- **11%** had limited or no contact.

Reasons for no contact included:

- Moved and not made contact to arrange new stoma nurse.
- Contact only with the manufacturer of stoma equipment.
- The allocated nurse had retired. The person was not aware of new contact.
- Some said they did not know, or chose not to answer the question.

Requesting prescriptions

4.4 stars was the average rating for people's experiences of requesting prescriptions.

Positive feedback on prescriptions

Nine people made positive comments. They included that they had not experienced problems, and that prescriptions were easy to order. Six people made positive comments about specific products and services they had used.

Issues with requesting prescriptions for stoma support products	Comments
Staff training and awareness Including lack of knowledge of products, staff attitude, and lack of privacy at reception.	*5*
Clinical staff In particular, the need for staff to be more aware that needs fluctuate over time. Some felt staff needed to be more flexible in their approach to care.	*4*
Communication challenges This included difficulties with communication between the GP practice, and other parties involved in the supply of products.	*4*
Information can be lacking Respondents said they had to do their own research to find out about new products because information was not proactive.	*3*

Impact on life

Having a stoma had impacted people's lives in many ways, often significantly.

- Several respondents were still adjusting to life with their stoma, or had come to terms with it. **Only one respondent said that it had made life better**. Overall, it is clear that the impact on day-to-day life had been completely life changing.
- One respondent had their stoma reversed, but this had an even greater negative impact on their life.
- The impact on **social life** meant one respondent had become almost **completely isolated**, others had **lost friends**.
- Five respondents described the impact on **work**, leading to retirement, working part-time, and changing roles.
- **Long journeys, and overseas travel, are avoided.**
- Although two respondents spoke about exercise, others worried about **body image** and **lack of energy**.
- **Sex lives** are also affected.
- The **emotional impact** on **family relationships** was also commented on.
- Even **finding suitable clothing** can be a problem, but one person described clothing which disguised the stoma.

People needed to plan their daily lives carefully, **fearing possible accidents or leakages**. This impacted their social lives considerably.

“Life changing in every way. Lost friends. No longer have social life. No energy. Leaks and accidents in public often due to difficult to manage high output. Feel dirty often. Tired. No longer able to work. No friends now. Alone. Nursing care. Often in hospital. This is for life now. Depression.”

“At first it had a huge impact, as my diagnosis and surgery happened so quickly and I had to give up work and retire early as a result. I have come now to terms with it and live a normal life.”

“I have had my stoma since I was 5 years old, so I have grown up with it. I try to be open with people I meet as my stoma is a Urostomy and they are less common that Colostomy/Ileostomy - so I try to educate people.

“Lots of clinical staff I have met through the years have never seen a Urostomy. Unfortunately, I have repeated UTI’s, which leave me feeling very unwell. On the positive side, leaks are a lot less common than when I was younger as products have vastly improved from when my parents had to spray glue on me and try to keep the bag on with big grey ‘kidney seals’.”

Suggestions for improvement

We asked people about what could have improved their experience.

The suggestions made by respondents were varied. They highlighted the need for connection with others who have shared lived experiences, and the need to be able to access ongoing accurate information on stoma care more easily. People also commented that they wanted improved communication between their GP practice, and the company providing their stoma equipment.

Finally, surgeries and hospitals need to ensure that staff are knowledgeable about stoma care, and the impact it can have. Also that the individual needs of those with a stoma vary, so flexibility in care is important.

People wanted to see
Ongoing information about managing life with a stoma, including nutrition, clothing and new products.
More groups and centres where people can come together to share information and experiences.
Easier access to surgeons and hospital staff to explain what and why decisions are being made.
Better trained staff in surgeries who have knowledge and understanding of stoma care and its complexities.
Improved communication between companies providing equipment and surgeries prescribing them. People felt this would prevent delays and avoid problems they currently experience.
Easier access to accurate information about stoma products, and not having to research this themselves.
Care available more locally.
More publicity about helpful information, or magazines, such as those from the Stoma Association.

“Being able to speak with someone else around my age, activity level and in full time work. Just to gain more confidence quicker (I was put in touch with a ‘buddy’, but their lifestyle was so different from mine). So much has been about me seeking the information for myself and pushing to get answers when things have not been so smooth. Even products that I know exist have been hard to access.”

“After a long conversation about my experience I think the person I was talking to had a new perspective. Maybe this way of thinking - the alternative to a stoma is much worse - might help some new patients?”

“And as for getting to have a conversation with the surgeon, impossible. Even getting an appointment with him was extremely difficult. Unfortunately, he was called out on an emergency so I never did see him. In my fourth year, he has discharged me to my local GP, without any explanation. I know I can contact my local GP if there are any problems arising, but it feels as if I have been dismissed.”

Final comments

We asked if there was anything else people wanted to share about their experience of living with a stoma.

Comments highlighted that people need:

- More information before, and after, their operation to support better decision-making.
- Access to staff that are better trained on stoma care, and who show more understanding about people's experiences of living with a stoma, and the varied impacts on people's lives.
- Improved communication about support available locally. This might include invitations to stoma events, workshops and groups.
- More information about how to cope with day-to-day living, such as information about nutrition, suitable exercise, and signposting to help and support.
- More publicity about how to avoid the need for a stoma.
- Wider awareness amongst other services and industries (e.g., airport security), to avoid embarrassing experiences.

"It's the medical people that cause most issues due to lack of understanding or preconceived ideas. I feel like a number, and I'm not treated like an individual. They think all stoma are the same, and we all have the same needs but we don't. They need to listen to us."

"I used to go to some stoma events/workshops about once a year but haven't been invited for many years, I don't know if such things still exist. But I found it useful to know about any new products or technology which had come to market."

Conclusion

The responses to this survey show that living with a stoma has had a profound impact on the day-to-day life of all respondents.

Every respondent has had a different experience, and many are struggling with life as a result of this operation. Others have adjusted and are living a good life with some limitations.

The analysis shows that receiving accurate advice and information before and after the operation on an ongoing basis and talking to others sharing this experience is important for people. People would also welcome improved access to, and increased knowledge and understanding amongst, clinical and surgery staff about stoma. This would help to improve the wellbeing of those living with stoma and alleviate the difficulties they often face.

Sometimes it goes well:

"I am so very grateful to everyone for all the wonderful help and support I have had. The care has been wonderful and has given me plenty of confidence that help is always at hand. A huge thank you to everyone!!"

But there are also profound difficulties faced by all living with a stoma:

"It affects every single part of my life and I have had to readjust to a lot of things. But the support I get from my husband, family and friends has been a massive boost. Otherwise, I feel I would have probably taken my own life on one of the many bad days I have had."