

Life with a stom







Life with a stoma

Having a stoma, temporarily or permanently, is a big change in a person's life. For some people, it might take a lot of time and adjustment to accept life with a stoma. Others, however, adjust more quickly. How you deal with it depends on you and your situation – there is no right way or wrong way to living life with a stoma.

In this book you will be introduced to Sif, Phillip, Marianne, Niels, Jamie and Sarah. They tell their personal, honest stories about their life with a stoma. They focus on what has been most important for them in accepting and getting used to living with a stoma.

These personal stories will take you around various topics: How to deal with suddenly breaking wind loudly; thinking about your stoma day and night; being bullied at school; a mother's concerns about her child's life with a stoma; life with a temporary stoma and life with a pouch; accepting life with a permanent stoma; having cancer; the reactions of relatives and friends to your life with a stoma; finding girlfriends; who to tell about your stoma; and much more. Each person has plenty of advice that they are ready to share with others who are in a similar situation.

Thank you – Sif, Phillip, Marianne, Niels, Jamie and Sarah – for being open-minded and being willing to tell your stories. You have done this to help others, and I am sure your stories will aid and ease life with a stoma for other people and their families.

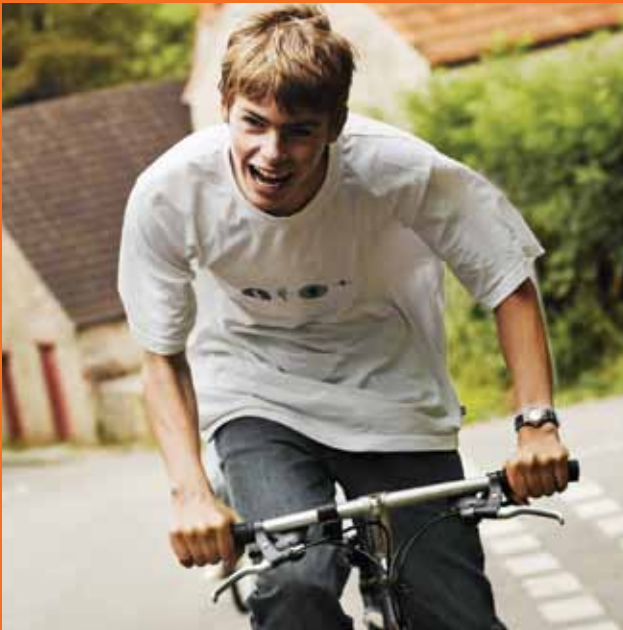
Yours sincerely
Dansac A/S



Anne Møller Frederiksen
Clinical Manager

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Jamie, 14



Phillip, 30



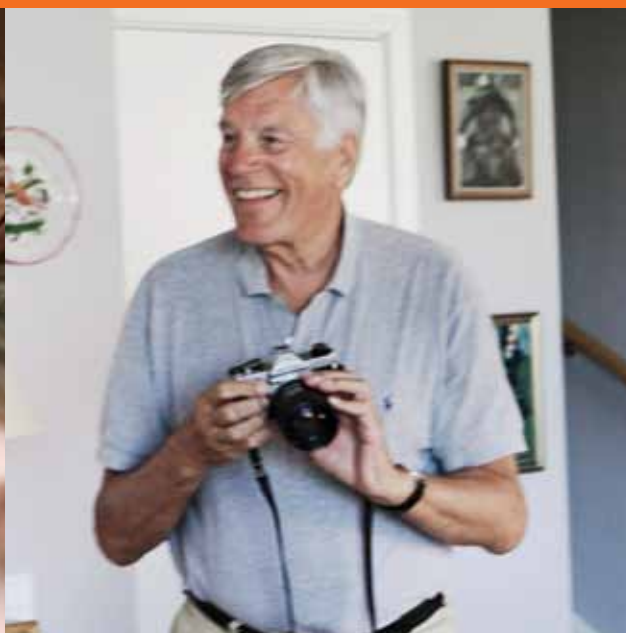
Sif, 33

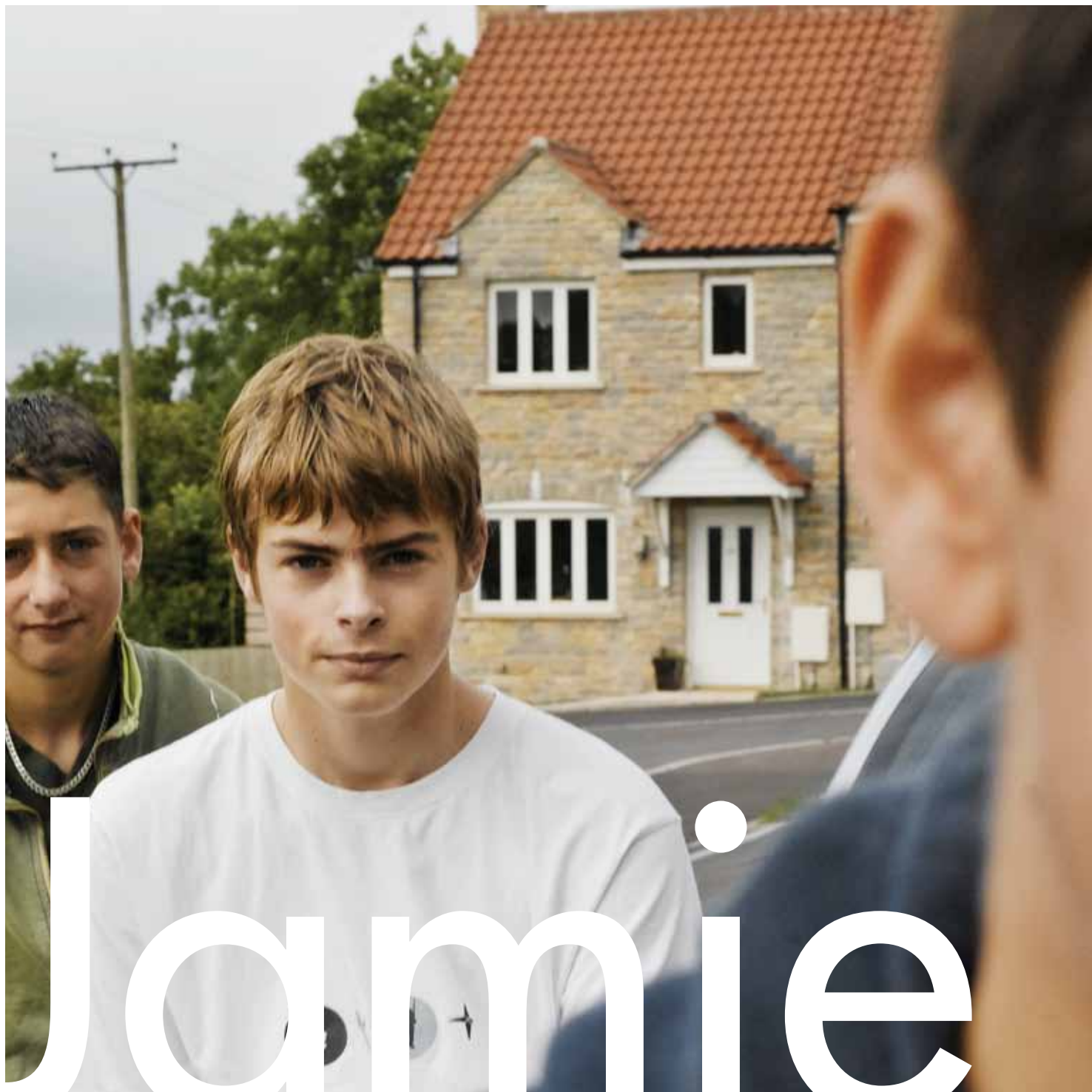


Marianne, 56



Niels, 70





Jamie, 14

Permanent colostomy

Now I can wear boxer shorts

"When I was eleven years old, the doctors suggested I should have a stoma operation. I'd never heard the word 'stoma' before. The staff at the hospital told me what a stoma is and how it works. I realised that a stoma could mean I'd avoid the daily mishaps I'd been having in my trousers, as having a pouch on my stomach would allow me to control my bowel movements. I was really excited about this. A stoma could also stop me from being teased. I could become a normal boy – I'd be able to go out and play, ride a bike, play football – and wear boxer shorts just like all my mates. I never had any doubt that having a colostomy was what I wanted. I reckon the doctors and nurses – and my parents – were more worried about whether a colostomy would be good for me or not than I was. I was sure of it. It was what I wanted."

Jamie, 14, had had problems controlling his bowel movements throughout his childhood. This was why he was so enthusiastic about the thought of not having to endure any more problems or bullying. Jamie's mother, Sarah, explains: "Jamie's life, and family life, was a bit

of a challenge before he had a stoma. Jamie couldn't control his bowel movements. We couldn't go anywhere without additional clothes, towels and anything else you might need to be prepared for an 'incident'. When Jamie was 9, he had a younger brother, and they were sharing nappies and towels. It ain't very pleasant for a 9-year-old, having to be washed and changed almost like a baby. Jamie's incontinence really limited what he could do."

The bullying, that was really bad. I realise that now!

"Jamie was teased to a point where he almost believed the bullying was justified. In retrospect, I can see how he felt before the operation. For one thing, there's the practical and uncomfortable problem of not being able to control your own bowels. Secondly, there's the issue of being bullied for something you cannot help."

A child should never have to accept being bullied. Jamie had reached a point where he almost had sympathy with the kids who were bullying him. That's just unacceptable." Jamie remembers: "One of the worst things was that I couldn't wear boxer shorts like my mates. If I wore boxer shorts, then the stools would slip down my leg. It was horrible. I was teased. That was really tough. I had a really difficult time."

When I saw the stoma for the first time, I felt so relieved. Actually, I thought that it would look huge, and would have swollen up. In fact, the stoma was smooth and round. I was so happy that at last I wouldn't be pooing in my pants any more. The nurses had already put boxer shorts on me in the recovery room. So when I woke up, I was wearing boxer shorts. It was just great!!

It didn't take long to learn how to change the bags myself and to work out how to deal with my stoma. For many years now, I've been changing my clothes and washing myself after an incident. I had pretty serious motivation to work out how to change the stoma bags myself. It gave me the freedom to go and play outside with my mates – without making a smell."





The stoma is part of my body

"The stoma is part of my body now, a natural part of my body. Just like my nose! I don't go around all day thinking "Oh my god – I have a nose." And the same goes for my stoma. After my stoma, I could do everything I hadn't been able to do before, when I couldn't control my bowels. I can go biking, play football, go swimming, travel, and do the same as my mates. So the stoma has become a natural part of my body, and my life!"

Jamie's mother adds: "The most remarkable about Jamie's stoma is the fact that we forget he has it at all. He lives just like a 14-year-old should live. Many people have found it hard to understand how Jamie can be so happy about having a stoma. Why is a 14-year-old boy so happy about having a stoma? It almost scares me. Because it might be a reaction against the old times, how horrid it was for him having to live with pooing in his pants every day and also being teased. It hurts a mother to realise that maybe I didn't get just how terrible it was for him before he had his stoma."

I've only told my best friends about my stoma

Jamie himself wasn't quite sure who he should tell about his stoma. And, according to his mother, making such decisions was a pretty fine line. For her, the most important thing was that Jamie set his own limits about how open he wanted to be.

Jamie remembers: "I chose to tell my very best mates. They've seen my stoma and seen me change the bag. When I had my stoma, I felt like showing them how it looked and how I do it. They think it's cool and now I do everything with them.

I've been very open about it to my family, my best friends and their families. But at the same time, I also think it's something very personal. I don't really want to tell people at school about it. Now I've got a stoma, I'm not teased about making a smell. That's fine with me – I don't feel like telling other children my age unless it feels right.

My family is very supportive. I'm the one who decides who needs to know about my stoma."

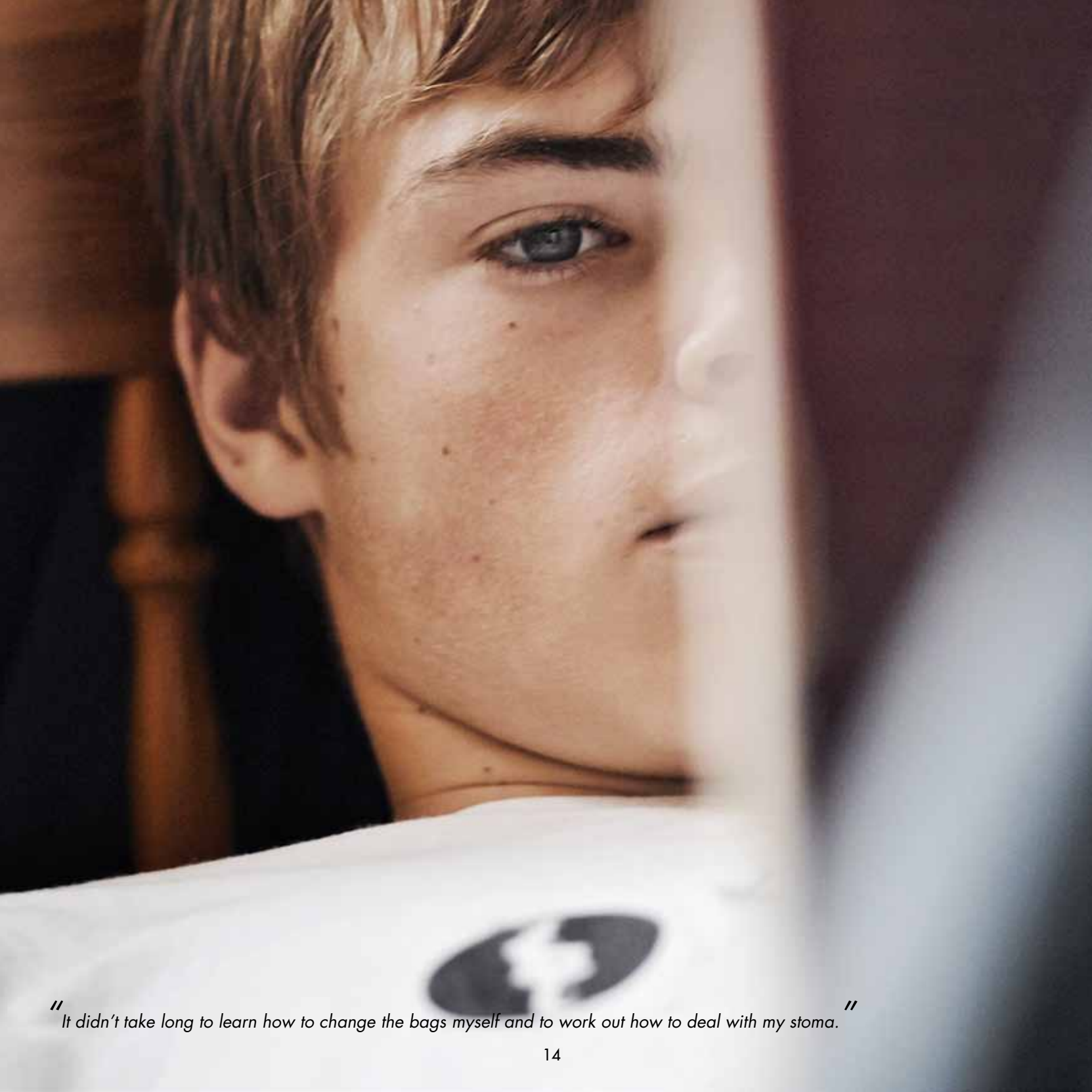
Look at pictures and search for information

"Look at pictures, search for information on the Internet or in books. Try to find someone you can talk to – preferably someone with a stoma who can tell you about his/her experiences. It may give you a better sense of what a stoma is and how you can still have a good life with a stoma." This is Jamie's advice to other children or teenagers who may find themselves in the same situation.

Jamie's mother has this piece of advice to other parents: "Find other people who have experienced it all, and ask them some of those questions you need to find answers for. In my opinion, it's a good idea to ask them when your child isn't there. If your child senses that you're very worried, he/she may worry too. The more you know, the calmer you'll be."

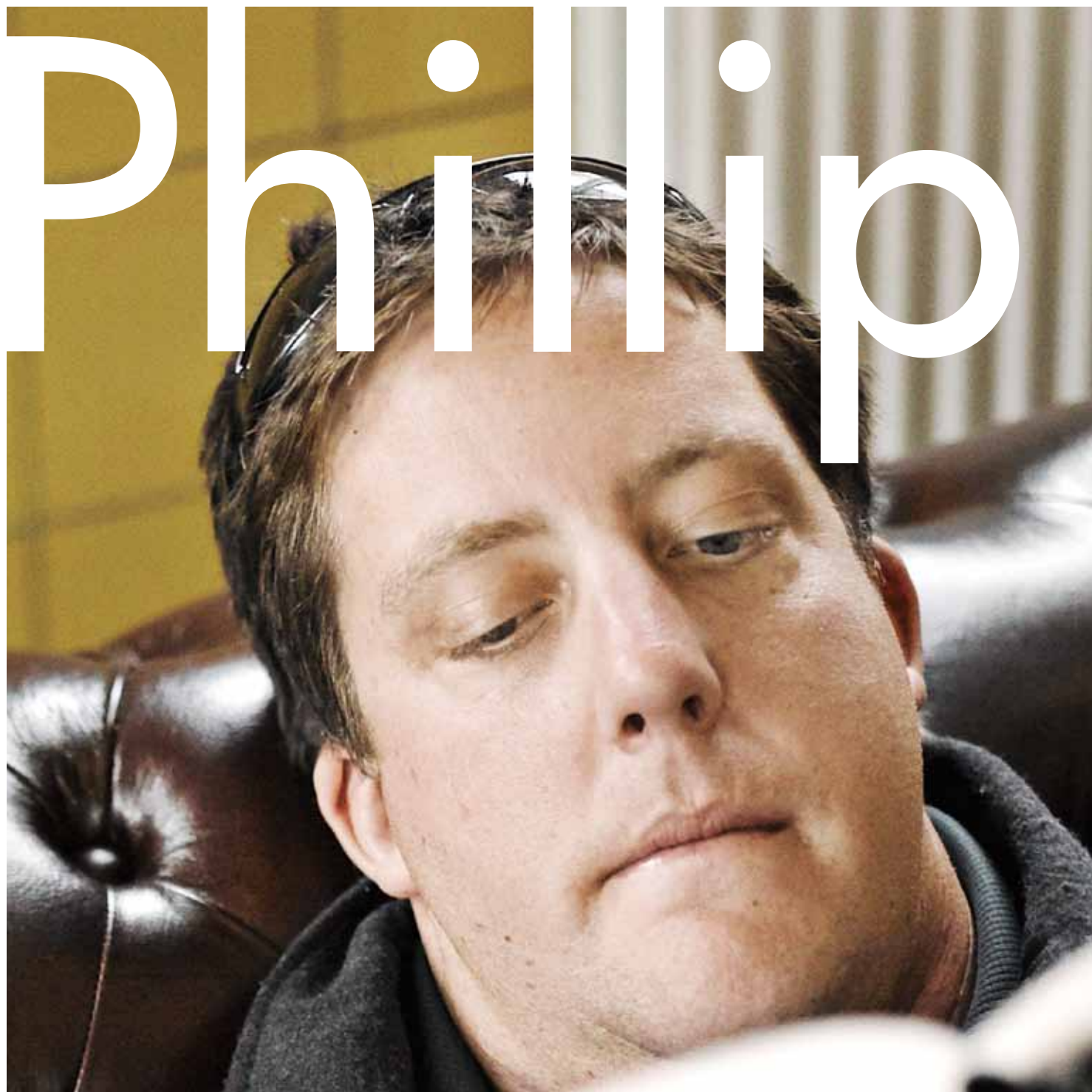
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“I’ve chosen to focus on the positive aspects of my situation. It’s so easy to think negative thoughts about everything in life. Actually, it’s up to you. I could make a list of the positive and negative aspects of having a stoma. But if I focus mostly on the negative aspects, I might become a bitter and resentful person.”

“I choose the positive. I’m well, I’m free, and I live the life I want to. Stoma or no stoma.”

Phillip, 30 Permanent Ileostomy

Rather a stoma than taking lots of drugs

“I didn’t cope very well with having bowel problems, having to take drugs all the time and all that being in pain. I’d rather live with a stoma for the rest of my life than have to take a lot of drugs.” So says Phillip from New Zealand, who had an operation to create a stoma eleven years ago, when he was nineteen years old. Phillip suffered from an intestinal disease called Ulcerative Colitis.

When you have a stoma, can you still go diving?

Understandably enough, some of the things which worried Phillip were whether he could continue his studies, and whether he could still go diving, once he had a stoma. Phillip remembers:

“Immediately after the operation, the thing I was most concerned about was whether I’d be able to carry on studying at university. It turned out to be no problem at all. And there was another thing that worried me: Now I had a stoma, would I still be able to go diving? Just before I fell ill, I’d bought a whole new set of diving equipment, and I really wanted to go diving again. There were

some practical concerns: What would happen if I had to use my stoma bag under water? It may sound silly, but it was a major concern for me. As it turned out, when the pain from the operation eased off, and my stomach started working again, neither diving nor my university studies were a problem. I did have a couple of mishaps to start with - it sure ain't nice when you manage to get it smeared all over your stomach. By and large, however, I came through that first period pretty easily - even if I did have some beginner's mishaps."

Embarrassed – no way!

Phillip has a very relaxed attitude to his stoma. Before the operation, Phillip's mum was one of the first people to tell him about stomas. But the hospital also gave him a lot of useful information, as a result of which he realised that 'in a way, a stoma is kind of like a sphincter which has been moved up onto your stomach and that your poo goes into a bag on your stomach rather than down the toilet.'

Phillip says he doesn't always feel like talking about his stoma. But, he says, "it's not because it embarrasses me. It's just because I don't want to talk about my illness. Of course, you know, I've been very sad at times about being ill and having to have a stoma. Who wouldn't prefer to be 100% well? But I've NEVER been embarrassed because of my stoma. In the beginning, it was impractical and unpleasant. But embarrassing – never. However, I do have my private sphere, and it can get tiring talking about my illness and telling the same story over and over again. But if people ask – then I answer them openly and honestly."

I have a good, active life

"Today, I have a really good life. If there is something I haven't done, it's not because of my stoma. I am the type of person who likes to have a busy life. I travel a lot. Both privately and in my job. I live in New Zealand, but travel for long periods throughout the year. I've climbed mountains and been miles away from civilised toilets. I just need to remember my stoma bags."



There have been occasions when I've been on a trip and I haven't had enough stoma bags. But then I just find somewhere I can get them. For a while, my mum sent me stoma bags when I was off travelling. Now, however, I find my own solutions as I go along. You can always find a hospital nearby. You may not find the exact same stoma bag as the one you use at home – but still, it works."

I focus on the positive

"I've chosen to focus on the positive aspects of my situation. It's so easy to think negative thoughts about everything in life. Actually, it's up to you. I could make a list of the positive and negative aspects of having a stoma. But if I focus mostly on the negative aspects, I might become a bitter and resentful person. I choose the positive.

I'm well – I'm free, and I live the life I want to. Stoma or no stoma."

Stoma – a neat way to find the right girl

Phillip has found that there can be some special advantages to having a stoma. It can be used to help decide about potential girlfriends. He says, "You can compare a body with a work of art. Which one's the most beautiful – a Rembrandt or a Picasso? He says," It all comes down to taste. The same goes for the human body. My body has scars on it, and a piece of intestine sticking out of my stomach. But I feel okay about it. I just look around and I quickly come to the conclusion that there's other people who might look worse than I do – even without a stoma!

Luckily, there are also some girls who think I look okay and want to be with me. Actually, what I'm really trying to say is that the stoma has provided me with a really good filter for potential girlfriends. Girls who can't cope with me having a stoma – well, they won't want to be with me in the long run anyway. So the stoma helps me to find girls who are really nice, really wonderful," Phillip concludes.





"I didn't cope very well with having bowel problems, having to take drugs all the time and all that being in pain. I'd rather live with a stoma for the rest of my life than have to take a lot of drugs."



"Today, I have a really good life. If there is something I haven't done, it's not because of my stoma."





Sif, 33

Temporary Ileostomy

I would think about the stoma around the clock

"Actually, you couldn't see that I had a stoma. But still, it was on my mind day and night. Could other people see that I had a stoma? Was the stoma bag full, and would it leak? The stoma was always on my mind in one way or another. So to be honest, having a stoma filled an enormous part of my life and took up a lot of my energy."

So says Sif, 33, a freelance photographer and mother of two. When she was pregnant with her second child, she started bleeding from her rectum. Sif remembers: "At first I thought the bleeding was related to the pregnancy. I was examined, and was told that I suffered from Ulcerative Colitis, which is an inflammation of the colon where it bleeds. It was a chronic inflammation which had spread through the whole of my large intestine. I had a Caesarean and hoped that the inflammation would ease off after the birth. But unfortunately that wasn't the case. The illness weakened me. I felt really sick – I was tired and exhausted because of the inflammation in my colon. I had just had a baby, and apart from having to take care of a newborn, I also had to take care of my 3-year old boy. There wasn't much energy left in my body."

The doctors recommended that Sif should have her colon removed and have a temporary stoma. In such a situation, following the doctors' advice seemed like the right thing to do. So Sif had the entire inflamed colon removed and had a temporary stoma.

I told most people around me about it

"It's been important for me to be open about my stoma," says Sif. "I told everyone – friends, family, acquaintances and customers – what it was all about: About my illness, the reason why I had a stoma, and how I was coping with it. I really feel that everyone's appreciated my honesty about my stoma."

My experience is that it has given me a more open, personal and relaxed attitude to living with a stoma. Believe me – once you can tell people that you poo out your stomach, you can tell them almost anything. It really breaks down the barriers!"

Other people must have a stoma too!

"I was really curious to know who else had a stoma! There had to be other people like me. But because you can't see it, it's hard to tell who does. At the hospital, the staff told me that of course there are lots of women in the same situation as me. I'm a photographer, and I wanted to find some of these other women who live with a stoma. I wanted to make a series of portraits of these women – including myself – to show the world that it's not a problem to live a completely normal life with a stoma. And that there are more people than you'd expect who are living with a stoma. It's just that you're not aware of it, because you can't see it."

Sif's stoma was temporary

Sif had a stoma for five months. It was then possible to make a 'pouch' as a replacement for her colon. In a way, a pouch is an interior stoma. The doctors fold the lower part of the small intestine into a U and sew in a 'container' - an interior bag! Your stools are then gathered in the pouch, which is emptied by a visit to the toilet, just like other people.

"Of course, a pouch is not the same as a genuine colon, and there were some 'teething' problems at the start," says Sif. "The first few months after I had the operation to fit the pouch, I had trouble keeping my stools in at night. When you don't have a colon anymore, your stools are always going to be thinner than if they went through your colon. The months after my pouch operation were tough, but after that, it started working quite well."

You cope

"My advice to other people who are going to have a stoma, or have one already, is to continue living your life the way you did before you got ill. Don't put life on stand-by because you're going to have a stoma, or you already have one."

When I was in the middle of it all, it felt insurmountable: Inflammation of the colon, giving birth, a newborn baby, the colostomy and another big operation when I got my pouch. But you can cope with the most incredible things when you're in the midst of it all. Really, it's before and after the crisis that everything seems insurmountable. When you're in the midst of it all, you cope", Sif concludes.







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" My family's very relaxed about the stoma. My oldest grandchildren have seen the pouch, and they were very interested in knowing how it works – I told them and there's been no issue with it since then. "



Marianne, 56
Urostomy

My stoma's just an extra fitting

Marianne has 28 years' experience as an assistant nurse, so when she discovered blood in her urine, she knew it wasn't good. Initially, however, her doctor treated it as a urinary infection. But that didn't help, so Marianne had an ultrasound of her bladder done.

The physician who made the scan could immediately see she had a growth on her bladder. And when Marianne later stood with the envelope in her hand and read the report of the scan, she had a strong feeling that something was seriously wrong – that she had bladder cancer. But then, they hadn't actually taken any tissue samples yet, and you do hear about benign growths.

Marianne pressed hard to get an examination. About a week later, she went into hospital, where they removed the growth and took a tissue sample.

I broke down – totally and utterly

Marianne remembers: "I got very impatient while I was waiting for the result. I called the hospital to find out if they'd received the result from the cell sample yet. They don't normally tell you your results over the phone. But I insisted that I WANTED to know, so they told me over the phone: I had cancer.

I broke down. Totally and utterly. I'd pressed hard to get the result, and even though I'd had a strong suspicion it might be cancer, when I heard the final result I just broke down. To hear the doctor say it!

The doctor was extremely kind – he told me that one option was to have my bladder removed and have an artificial bladder made from my small intestine. The other option was to have a stoma. I chose the stoma.

I can't rationally explain why I chose to have a stoma rather than an artificial bladder. It just suited my temper more. I'd heard good things and bad things about both options – but I chose the urostomy."

Some people get false teeth, other people get a stoma

"I knew about stomas from my time working as an assistant nurse, and from my husband's work. But it's one thing to be a professional, quite another to suddenly be the person with the stoma yourself. My father had had bladder cancer, and he'd had a stoma nine years ago. My father and I were operated on by the same surgeon. So I knew what a stoma was, from my private life as well. But again – when you get something like that yourself, it's something different entirely.

Before I had my stoma, I was wondering if I'd be able to do all the things that I'd been able to do before – run, play badminton, climb trees with my grandchildren. What about my clothes? Would I have to buy a new wardrobe? Would it restrict my social life? I had all these thoughts and questions going through my head before I had the stoma. But still, I never doubted that a stoma was the right solution for me.

Later on, I discovered there was nothing I couldn't do. I look upon my stoma as an 'extra fitting'. Some people get false teeth, others get a nail put in their knees. I've got a stoma – a bag on my stomach. My husband started as a qualified nurse, which means he knew about stomas and was quite relaxed about the whole thing. We just want to go on living our good life. We've bought a shop – a bookshop – which we love running. We want to be together with our children and grandchildren. To live life to the full – even with a stoma."

The cancer was the main concern – the stoma came second. After Marianne had been diagnosed with cancer and decided to have a stoma she received lots of information about cancer and stomas. But for Marianne, the cancer was her main concern. So she concentrated on finding out as much as she could about the disease: From doctors, on the Internet, and from The Danish Cancer Society.

The stoma came second, and afterwards she could hardly remember what she had been told, and what she knew already from her work. As she says: "I knew enough to be well prepared. But I was more concerned about the bladder cancer. My stoma was just an extra part which would allow me to carry on with my life. I didn't really think about the stoma that much. I just wanted to be well – with no cancer in my body."

The size of a shopping bag

"In the beginning, I was obsessed with the sound the pouch was making. In my mind, the stoma pouch was the size of a shopping bag. I was terrified that my pouch would over-fill and fall off. At first, I was always running to the toilet to check my pouch. But for the most part, it was all in my imagination. The pouch worked well, and I've only had one accident – which happened in an airport. That was really uncomfortable. So it's very important for me to always carry an extra bag with me, so I can replace the pouch when I need to. But as I say, it's only happened once."



"I look upon my stoma as an 'extra fitting'. Some people get false teeth, others get a nail put in their knees. I've got a stoma – a bag on my stomach."

At the beginning, Marianne recalls, she was convinced that the stoma pouch was "rustling". "There was nothing my husband could do to convince me that it didn't make as much noise as I thought it did. I thought that he was trying to protect me, so I wouldn't get upset about it. But actually, he really meant it. He honestly couldn't hear the noise I was hearing. After a few months, I'd already got used to it. I have to admit that the pouch doesn't make loud squelching noises, nor does it take up as much space as a shopping bag. I can wear the same clothes as before, and I haven't had to get a new wardrobe.

My family's very relaxed about the stoma. My oldest grandchildren have seen the pouch, and they were very interested in knowing how it works – I told them and there's been no issue with it since then. Children take things like that the way you put it to them. We were very worried about how they'd react." "If you yourself are open and relaxed, your children will be relaxed about it too," says Marianne.

Look for information and be open-minded

"My advice to other people who find themselves in the same situation as me must be: Look for information wherever possible. In spite of my professional background, I still sometimes lacked the specific information I needed about stomas. So my advice would be to find out as much as you can about how to live with a stoma – ask for help to find someone to talk to. Someone who's been in a similar situation.

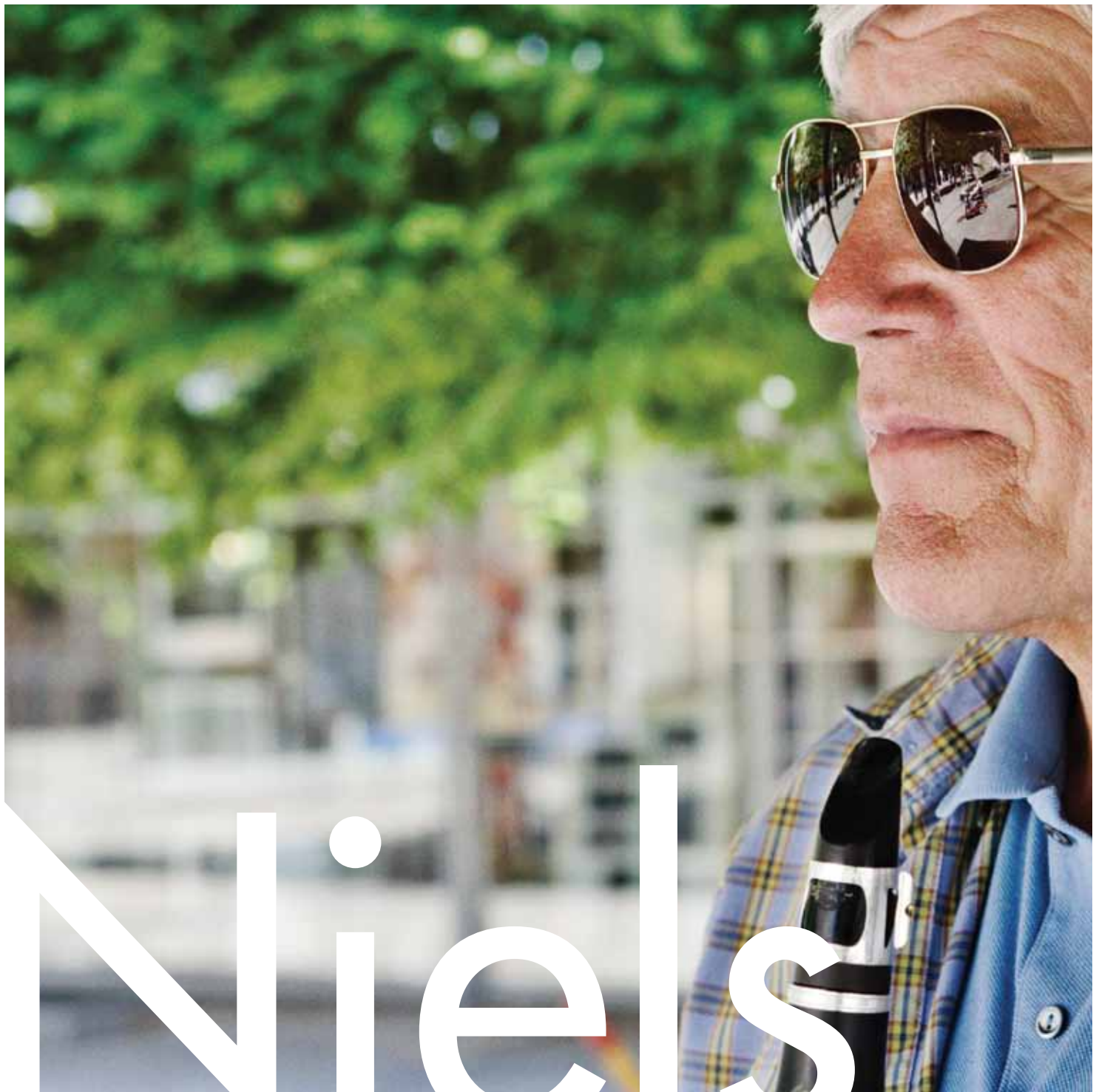
Be open about it. Thanks to my openness, I've experienced unexpected help and support. For example, one of our bookshop customers offered to let us stay at her house in Italy. It was a great experience, and it gave me the energy to move on," Marianne concludes.

"Before I had my stoma, I was wondering if I'd be able to do all the things that I'd been able to do before – run, play badminton, climb trees with my grandchildren."





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"Without the stoma, I wouldn't have been cured of my cancer. I think this thought has helped me and my wife accept my life with a stoma."

Niels, 70 Colostomy

Grandpa has a 'farting bag' on his stomach

In 2005, Niels was diagnosed with rectal cancer, and after radiation therapy and chemotherapy, he had an operation and got a permanent colostomy. Niels, 70, describes his experience of having a stoma: "My children have supported me all through the process. They were very open in the way they showed their concern, and very curious about the stoma. They all tried to learn about stomas and understand what it would mean for me to live with one. They have been really, really sweet. Then there are my grandchildren.

I chose to tell my little grandchildren that I have a stoma. Children have their own way of dealing with such things. On Christmas Eve, my eight-year-old grandchild was

sitting next to me. Suddenly there were farting sounds coming from my stoma. My grandchild looked at me and said indignantly: "Really, grandpa!" I lifted my sweater and showed her the stoma bag. And then she exclaimed with a big laugh: "Grandpa has a 'farting bag' on his stomach." When she discovered that her grandpa had a 'farting bag' on his stomach, she was really excited."

Good advice from a friend

Niels had a friend who had had a similar operation. When he heard about Niels's situation, he invited Niels round for dinner to show him what a stoma was. "I am a retired dentist, and I know about bodily functions and understand the physiology of how a stoma functions. But simply understanding the theory isn't enough. As a patient, this was all completely new to me, and because of my illness, I had to get used to a totally new situation." Niels was very happy to have such a good friend, who could be very open about his own situation. He remembers: "He showed me his stoma bags, how he washed the stoma and how he changed the stoma bags. In short, he told me pretty much everything about his experiences of living with a stoma. It helped a lot, and it didn't take me long to accept that I was going to have a stoma."

His wife accepted it too

Niels says, "Of course, it's quite a change to see me with a stoma on my stomach. Especially in the period immediately after the operation. My stoma is permanent, but I've got used to it now. But having a stoma was a radical change. My body looks different. A lot of people might be wondering how my wife reacted. My wife is happier to see me with a stoma than having to think about me still having cancer cells in my body. Without the stoma, I wouldn't have been cured of my cancer. I think this thought has helped me and my wife accept my life with a stoma."

My stoma emergency bag

By and large, Niels lives in exactly the same way as he did before he got ill. He does the same things as he used to do. He enjoys his family, travels, goes bicycling,



draws, and paints. And he also plays the clarinet. "I play the clarinet in a jazz band", he says. "All the members of the band know that I have a stoma. We play gigs at various events, and one day we were playing outside in a garden. In the middle of the performance, I could suddenly smell that the bag was leaking. So I had to go and change my stoma bag in the garden shed.

That kind of thing can happen to anyone who's got a stoma. Therefore I carry my 'stoma emergency bag' with me at all times. It's like a small handbag with everything I need in it to change the stoma pouch. I've got some extra stoma bags, some tissues, and a few bin bags. It's really important for me to remember the bag – every day, no matter where I'm going. If anyone asks me why I am always carrying that bag around with me, I say: "Because I've got a stoma". And then there's not much more to say about it."

Playing golf with a stoma on your stomach

"A lot of people ask me if my life has changed since I had the operation. Has my quality of life changed? I had cancer and now I've got a stoma. So of course my life has changed. When you're diagnosed with cancer, it gets you thinking. To have a stoma on your stomach is a visible, physical change to your body. But my quality of life has not decreased because I have a stoma. Despite my stoma, I can still do a lot of the things I've always loved. I've played golf for 20 years. Just as you can swing a golf club with a pipe in your mouth, it's no problem to swing a golf club with a stoma on your stomach.

My advice to other people who might have to have a stoma would be: Accept the situation. You don't have a stoma unless there's a really good medical reason for it. Listen to what other people who've been in the same situation have to say, and learn from it. Don't be embarrassed because of your stoma. For heaven's sake: There's no reason to be embarrassed.

Your life has been prolonged, possibly improved, and maybe even saved by a stoma," Niels concludes.





"There's no reason to be embarrassed. Your life has been prolonged, possibly improved, and maybe even saved by a stoma."

"My quality of life has not decreased because I have a stoma. Despite my stoma, I can still do a lot of the things I've always loved."



Anne + Kelsie (dada-
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HARVEY



Dansac Limited
Victory House
Vision Park, Histon
Cambridge CB24 9ZR
United Kingdom
Telephone: 01223 235100
dansac.ltd@dansac.com
www.dansac.co.uk

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