

eter Kilvert has fond memories of Malta. On his way to Australia in 1956, he and his family berthed here overnight on their way down under. Before he relates the heartbreaking story of his daughter Alice, he takes a moment to relive Malta's narrow streets and friendly faces.

"I remember being on the ship and haggling with a seller on land. Once we were happy with the price he had proposed, we put money in a little basket and lowered it over the side of the boat in exchange for the goods. I bought my mother a beautiful, silk scarf for five shillings!"

Sixty years later and once again he finds himself connecting with the island as he

speaks candidly about his 15-year-old daughter's death as a result of Toxic Shock Syndrome, and the positive awareness campaign that he and his wife have launched since.

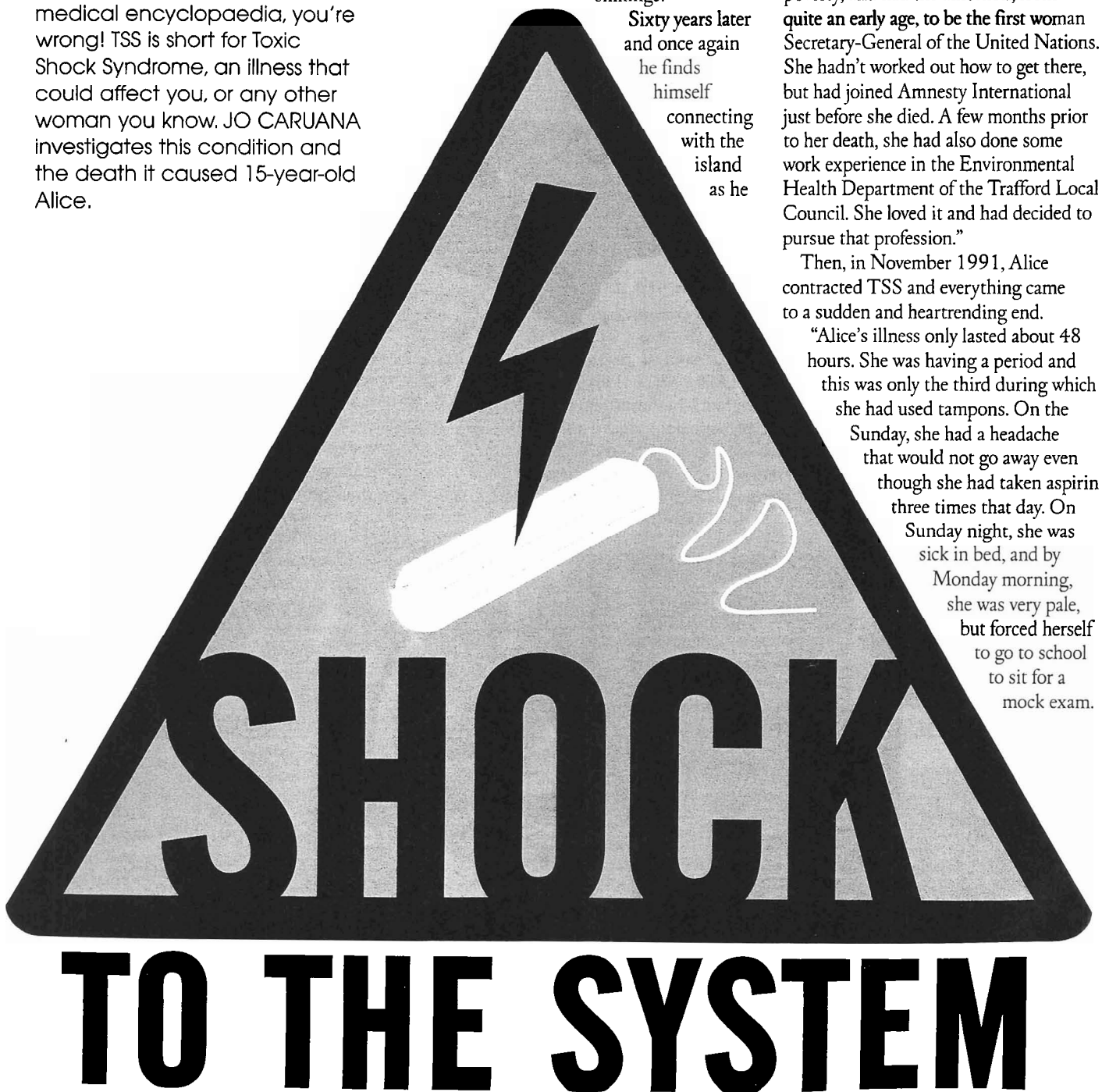
"Alice was a wonderful person; she was friendly, chatty and generous, forever volunteering to do things. I remember, as a child, she'd start saving her pocket money from June so that she could buy everybody a Christmas present. She went to dancing lessons from an early age and was very nimble on her feet. She was also keen on a band called James and went to one of their concerts in Manchester.

"She was concerned about world poverty, and had the ambition, from quite an early age, to be the first woman Secretary-General of the United Nations. She hadn't worked out how to get there, but had joined Amnesty International just before she died. A few months prior to her death, she had also done some work experience in the Environmental Health Department of the Trafford Local Council. She loved it and had decided to pursue that profession."

Then, in November 1991, Alice contracted TSS and everything came to a sudden and heartrending end.

"Alice's illness only lasted about 48 hours. She was having a period and this was only the third during which she had used tampons. On the Sunday, she had a headache that would not go away even though she had taken aspirin three times that day. On Sunday night, she was sick in bed, and by Monday morning, she was very pale, but forced herself to go to school to sit for a mock exam.

What does TSS mean to you? If you are inclined to think it is an anagram better suited to a text message than a medical encyclopaedia, you're wrong! TSS is short for Toxic Shock Syndrome, an illness that could affect you, or any other woman you know. JO CARUANA investigates this condition and the death it caused 15-year-old Alice.



Later, though, her teacher said she looked like she had the flu and she was sent home, where she went straight to bed.

"By dinner time, she appeared to have a slight temperature, but at 7 p.m. was alert enough to talk about the TV programmes she had missed. By 10 p.m., however, she had deteriorated and came downstairs very disoriented and talking to us in French."

By the following morning, Alice's temperature had risen and her breathing had become shallow. By the time the doctors took a blood pressure reading, it was so low that it did not register and they diagnosed her as having meningitis, or Toxic Shock Syndrome. They later eliminated the former after conducting a lumbar puncture.

"We were so relieved that it wasn't meningitis as we presumed TSS was the lesser evil of the two. However, at about noon, there was a commotion, and we were informed that Alice had gone into cardiac arrest, but had been saved. Unfortunately, when a second cardiac arrest followed, nothing could be done and we lost her.

"How could our daughter have died of something I had never even heard of? As a health and safety officer by trade, I searched through my files at work, but could find nothing on the syndrome. It was only once we were put in touch with the Women's Environmental Network in London that we found out some more information. Looking back, I'm amazed that the doctors knew how to diagnose TSS so quickly. Even today, it's so often misdiagnosed and a bit of an enigma."

Following Alice's death, her parents realised the importance of raising the profile of TSS and creating more awareness about this confusing syndrome.

"I am sure Alice did not know about TSS; if we had all been more aware, she might have been here now. In the name of research, my wife Jenny and I formed a group, which included some of Alice's friends and some of our friends. We met every month and produced a leaflet, a short information video and then a website. With the help of the Women's Environmental Network, we built up many contacts with TSS victims and families of those who had died of TSS.

"We decided to establish a Tampon Alert Day on June 8 [Alice's birthday], which has since been stretched to National Tampon Alert Week in the UK, and June 8 went on to be called International Tampon Alert Day."

Since then, the group has successfully lobbied the Westminster Parliament for improved TSS warnings on tampon packs. Their website has been adopted by those of many health organisations, and Peter and his wife aim to keep in contact with TSS survivors and other families with relatives who have died from the illness.

"There is plenty of information out there about TSS, but so many people do not tend to read labels until something goes wrong! So many people think that it could never happen to them, but it could! In the UK, there are around 20 cases a year; in Malta, there may only be one case every few years, but if awareness can save even one person, then our cause is worth it.

"There is so much misinformation out there too. One myth is that TSS is caused by a forgotten tampon, but that's not true. It can kick off after only two hours, so changing tampons regularly is important. The biggest risk factor is absorbency; the higher the



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absorbency, the higher the risk. In the old days, tampons were made of cotton and there was no TSS. Then they started to use a substance called rayon and cases started to occur. In 1980, in the US, a company called Procter & Gamble

introduced a brand of tampons, made from an even more absorbent man-made material called carboxy-methyl cellulose [CMC]. You could use just one tampon for your whole period. That year, there were almost 1,000 cases of TSS and 38 deaths, so it was withdrawn from the market. Today, most tampons still contain rayon and TSS continues. The safest option is an all-cotton tampon, towels, reusable rubber cups, or reusable sponges.

"Tampons are such a useful product that to ban them would not allow free choice. There is only a slight risk, and as long as everybody knows what the symptoms are and are confident that they could get themselves to a doctor, or to hospital, then they can take a known risk. However, I do think that the labelling should improve. My feeling is that they should put a warning on the pack, but haven't done so because they don't want to draw anyone's attention to it."

As yet, there is not enough research to suggest that people with a particular gene, or condition are more prone to TSS.

"A study in the US highlighted that many cases were of northern European origin, while another found a link to people who had allergies. Interestingly, we've found that almost all the girls, or women on our list were keen on fitness, or played sport! But overall, it seems to be quite random."

If you think you might be showing signs of TSS, remove your tampon and get to the doctor, or hospital as quickly as you can.

"It is so important not to overreact, but I can't help thinking that if we had been more aware of the symptoms, then we wouldn't be in the situation we are now."

Peter and Jenny Kilvert's website [www.tamponalert.org.uk](http://www.tamponalert.org.uk) stands as a lasting memory of their daughter Alice, and serves as an information point for anyone looking for further advice, or facts about the syndrome. ►

## SYMPTOMS OF TOXIC SHOCK SYNDROME

- ALWAYS BEGIN AFTER A PERIOD.
- EARLY SYMPTOMS MAY INCLUDE A HEADACHE AND/OR SORE THROAT.
- ACHING MUSCLES AND A HIGH TEMPERATURE.
- VOMITING, DIARRHOEA, A RED RASH, DIZZINESS AND CONFUSION.
- VERY LOW BLOOD PRESSURE.
- NOT ALL SYMPTOMS MAY OCCUR; THEY MAY NOT ALSO PERSIST.

## TO REDUCE THE RISK OF TSS

Since the condition derives from a bacterial infection with a particular Staph species, the following are recommendations for prevention:

- Report and treat abnormal vaginal discharge and infections promptly.
- Do not use tampons in this case until treatment is successful.
- Use the lowest tampon absorbency needed at each stage of your period.
- Wash your hands before and after use and handle tampons as sparingly as possible.
- Change tampons at least every four hours.
- Do not use them overnight.
- Never use more than one as this can lead to a 'forgotten tampon'.
- Report a 'lost' tampon immediately.
- Avoid using tampons continuously throughout your period. Alternate with towels, particularly at night.
- Use a towel towards the end of your period.
- Do not use towels if you have unusual discharge.
- Try to use tampons made of organic cotton.

## FROM THE DOCTOR

TSS is a condition that is primarily associated with the use of vaginal tampons in 50 to 70 per cent of cases, says Dr Donald Felice.

Originally reported in the media in the 1980s, TSS is characterised by an acute, febrile illness, associated with rashes, sore throat, dizziness, diarrhoea, vomiting, muscle pains, and may progress rapidly to shock and general system failure, including kidney and liver, he explains. If not treated early and aggressively, it can lead to death in five per cent of cases.

The incidence of TSS is in the region of five per 100,000 women of reproductive age, and has decreased rapidly since manufacturers have changed the absorbency and composition of vaginal tampons. The original cases were more frequently associated with super absorbent and chemically enhanced varieties.

The frequency in Malta must be extremely rare since the women of tampon age would be about 40,000, and not all would be using tampons, says Dr Felice.

"As far as I know, and this is the experience of my colleagues, we have never seen a full-blown case of TSS locally."

If established, the treatment of TSS involves aggressive antibiotic therapy, intravenous fluids and systems support. The successful cure rate is in the region of 95 per cent.

*Donald Felice, MD, FRCOG, is a consultant obstetrician and gynaecologist, as well as senior lecturer in obstetrics and gynaecology at the University of Malta. He is also president of the Malta College of Obstetricians and Gynaecologists. ■*

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