



Alison Brown¹ describes the origins and

evolution of the Mouth Cancer Foundation over the past 20 years, and meets key members of the charity's team.

The Mouth Cancer Foundation: its history and legacy

Author information

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Introduction

The Mouth Cancer Foundation (MCF) celebrates 20 years as a registered charity in May 2025. The MCF is one of the smaller cancer charities but over the last 20 years has supported countless people and families with their cancer journey. They run campaigns to raise awareness of head and neck cancer as well as supporting the dental industry with leaflets and advice.

I was privileged to be asked to become an Honorary Ambassador for the charity in January of this year. The 20-year anniversary has prompted me to look at the history of the charity, how the charity has grown and the wonderful people who support the growth and direction of the charity for those families and people who have been on or are on a head and neck cancer journey.

History

In 2002 Dr Vinod Joshi set up the Restorative Dentistry Oncology Clinics' Mouth Cancer Awareness website to complement the work he was doing at the clinics he ran at St Luke's Hospital, Bradford and Pinderfields Hospital in Wakefield.

The website experienced phenomenal growth over the first two years, especially the message board facility, which became a robust online support group. This convinced the Consultant in Restorative Dentistry to establish the Mouth Cancer Foundation in June 2004, a not-for-profit organisation with the intention of becoming a registered charity. In May 2005, the Mouth Cancer Foundation became a registered charity, No. 110929.

The charity's mission

The MCF is 'dedicated to raising awareness and support for those suffering from or at risk of mouth cancer, throat cancer and other

head and neck cancers, as well as providing assistance and information on mouth cancer for families, friends and carers.

'The promotion, protection and education of good health is key to raising awareness of mouth cancer. The charity aims to inform the public about the signs, symptoms, facts and figures and key causes of mouth cancer.'

Objectives and strategy

The objectives and strategy of the MCF are:

- The promotion and protection of good health among those suffering or at risk of mouth, throat and other head and neck cancers by the collation and dissemination of relevant information to the public and by the provision of support to patients, carers and health professionals
- Mouth cancer awareness with emphasis on early detection, professional screening and prevention
- Saving lives by raising self-awareness and self-checking for early detection among the public
- Improving lives at a point of need through online support, a community forum, and a dedicated patient and carers helpline
- Offer support at a grass roots level with grant schemes such as the Support Group Awards, Charity Project Awards and the annual Mouth Cancer 10 km Awareness Walk
- Providing free information and awareness materials to the dental and medical professions, pharmacies, educational establishments, public and communities.

The impact of the MCF

The MCF has been helping to raise awareness, support and influence the head and neck cancer world through education and support for almost two decades. The charity has grown over the years as has the support it has given to those who need it most.

The MCF is a busy little charity with around 100,000 visitors to the website each year as well as being one of the leading cancer charities visible on Facebook, Twitter, Instagram and YouTube, reaching an audience of millions of followers each week. Our ambassadors regularly attend dental, medical and care sector related events, exhibitions, webinars and workshops raising awareness of all head and neck cancers.

The charity disseminates thousands of free marketing materials, posters (available in multiple languages), leaflets, flyers and handbooks, every year increasing awareness and working closely with dental and medical professionals, hospitals, schools and pharmacies and nursing homes.



Elizabeth Ayto Laverack



Laura Naden

Facts and figures

- Since its launch in 2015, more than 10 million consumers have been reached via the Mouth Cancer Foundation Self Examination campaign (<https://www.mouthcancerfoundation.org/self-examination/>), encouraging the general public to check themselves for mouth cancer monthly
- More than one million people receive help via the charity's website each year
- More than £60,000 has been raised by people taking part in the annual MCF awareness 10 km walk
- More than 25,000 leaflets and posters are given away free each year
- More than 13,000 followers benefit from the social media platforms, which include the MCG closed Facebook Group
- More than 5,000 patient handbooks are distributed to hospitals each year
- More than 1,000 dental professionals are educated on how to carry out a thorough head and neck cancer examination
- More than 250 telephone calls are made to the charity's helpline each year, assisting patients and carers
- Thirty support groups across the UK helped with more than £28,000 in grants in the annual support group awards
- More than 15 people each week attend a weekly online support group meeting
- Twelve not-for-profit head and neck cancer organisations receive help with £14,00 in grants in the annual charity project awards.
- For every pound that is raised 80p is spent directly on patients.

Ways to help

The annual Mouth Cancer 10 km Awareness Walk is now in its 19th year and is held in Hyde Park, London in September. Between 1 October and 30 November you can also walk as many times as you like

on your own or with your family and pets in the comfort of your own area to raise money. The charity is encouraging as many people as possible to step out and make a difference during Mouth Cancer Action Month. Details can be found at www.mouthcancerwalk.org.

This also overlies the Mouth Cancer Action Month in November. If we can raise the profile of mouth cancer, we can help change people's lives. Hopefully in dental settings we are doing this all year but through the month of November we can give mouth cancer awareness a higher profile throughout the dental setting and nationwide.

The team at the MCF

The team comprises of eight trustees, 14 clinical ambassadors, four patient ambassadors, four people's ambassadors, and ten honorary ambassadors.

The daily running of the charity is undertaken by Elizabeth Ayto Laverack and Laura Naden (Administrator).

Elizabeth Ayto Laverack

Liz has a public relations and journalist background and became involved with the MCF in 2005 at the very start when the Foundation gained charity status. At this stage there was an annual charity walk and mouth cancer leaflets were distributed at dental conferences.

After ten years the charity had grown, although it is still small in comparison to other charities. Laura Naden joined the charity part time as an administrator. Laura became involved with the MCF when her father was diagnosed with mouth cancer.

In the 20 years Liz has been running the MCF the charity has been able to provide grants for mouth cancer patients to bank their voice. Speech and language therapists contact the MCF when their patient's treatment

other agencies who also support our patients.

Most people will be surprised by how small the charity is and how we support mouth cancer patients. What are your ideas for the anniversary year?

I agree we should make 2025 a big year for our charity and the Walk. All the ambassadors and volunteers can try and pick one project, from a talk, coffee morning, knitting competition, a sports day (eg golf or footie match), for 2025 and we at MCF can support and publicise this on our website.

Jocelyn Harding

Jocelyn (Joss) Harding is a clinical ambassador and President Elect of the MCF. Joss has also written a separate article for this special issue of *BDJ Team*.

Joss began her dental career in the Royal Navy in 1987 and qualified as a dental hygienist in 1992. She has been with the Confident Dental and Implant Clinic in Gloucestershire since 2007. She played a key role in updating the 2021 'Delivering better oral health' guidelines for mouth cancer prevention and early detection while representing the British Society of Dental Hygiene and Therapy (BSDHT), as well as involvement with the UK Oral Management in Cancer Care Group.

Joss has published a peer-reviewed textbook, 'Care of head and neck cancer patients for dental hygienists and therapists', with all royalties donated to charity. Jocelyn's career reflects her dedication to advancing dental care and supporting patients living with cancer.

Interview

How long have you been involved in the charity?

Joss: I have been involved in the charity since 2018. It came about after I had a discussion with Krishan Joshi at a dental show about the limited information available for head and neck cancer patients in relation to mouth care.

Besides being President Elect, do you have a specific role?

I am Clinical Ambassador – supporting the MCF head and neck cancer patient ambassador Karen with weekly Zooms, supporting Alison with queries that arise with the charity helpline, and presenting on behalf of the charity at dental conferences.

How has the charity evolved since your involvement?

The information sharing has improved significantly with the charity now being

seen more visibly on social media and other platforms. This is one benefit coming about since the pandemic, enabling many of the public to become more confident with online platforms.

This means patients and caregivers have more ways of connecting with others who have personal experiences. The success of the Monday night Zoom group and Facebook group are testament to this.

cancer so through my social media platform, I began to raise awareness and made myself contactable for other patients and family members. My raising awareness bought people from various countries looking for support. I also had journalists wanting to get in touch and radio stations and I was happy to talk about my experience and encourage others to seek medical advice if they were concerned.'

'I understood what it was like to be "invisible", "unheard" or just lonely at times and I wanted every member to feel listened to always.'

What are your hopes for the charity in the future?

My pipedreams for the future are: I would like to see the charity building further connections with health care professionals, dental practices and hospitals in order for patients and caregivers to easily access MCF support from diagnosis onwards.

I would like to see the charity spearheading government change; for head and neck cancer patients' mouth care to be standardised, initiated with free dental checks and then in time consider subsidised dental care after treatment. This can then bring head and neck cancer after care in line with patients who receive after care of other cancer treatments.

Karen Liesching-Schroder

Karen Liesching-Schroder is a patient ambassador for the MCF.

Karen shares her background:

'My name is Karen Liesching-Schroder, and I was diagnosed in February 2016 at the age of 43 with tongue cancer. I did not expect a diagnosis like this because I have never smoked and didn't drink much alcohol, and I hadn't really heard much about this type of cancer. I was a runner and relatively "healthy". I had the side of my tongue removed and a neck dissection, then I had a PEG fitted into my tummy and had six weeks of intensive radiotherapy. Six months later I had another portion of my tongue removed from under my tongue which then led to issues with swallowing and poorer speech. I realised after about a year that not many people knew much about this

Interview

How long have you been involved in the charity?

Karen: I have been involved with the Mouth Cancer Foundation properly for four years. I was delighted to be asked to become a patient ambassador and said yes instantly.

How did you become involved with the charity?

I first encountered the charity when I was a guest speaker at the House of Commons in 2019 at the launch of Mouth Cancer Action Month, so just before the pandemic. Then the Foundation set up a virtual coffee morning support Zoom meeting with Jocelyn Harding, which I attended every week during the first lockdown because all the face-to-face support groups had closed down. This became a huge source of support, and I encouraged members from my local support group to attend which they did. From there, if Joss was unable to host, I offered to step in as I knew how important this support was to us as patients, and between Joss and me the Zoom group has run every week without fail since 2020 which is pretty remarkable. It is really lovely when we co-host together. We are the only charity that offers a weekly Zoom meeting for support as most support Zooms with other charities are once a month, and the patients were so grateful for this connection. The zooms went from 40–50 minutes with an abrupt close which patients found frustrating, so they asked for longer and some even offered to pay towards the subscription. Luckily though, the MCF

stepped in and paid, and we went from 50 minutes to two hours of support (sometimes two and a half hours if it has been required).

Do you have a specific role?

The Mouth Cancer Foundation had an online forum for patients before I became involved; but now that social media has such a big presence, a different type of forum was set up and I was asked if I would like to be the admin. Again, I didn't hesitate to agree, as long as the Foundation set the page up for me as I am not technical, and it needed to be private and secure. I am a member of quite a few head

patients and family members during their time of need.

How has the charity evolved since your involvement?

Despite only being a small charity, the Mouth Cancer Foundation is going from strength to strength and I am so proud to be associated with it. My role as a patient ambassador is to support not only the patients but their family members. These cancers and their treatments are brutal and so isolating; quite often we hear of the excellent care from diagnosis, surgery through to treatment, but patients

nationwide. I have found this year, I have been invited to speak out about my experiences and in doing so, not only raise the profile of mouth cancer but also raise awareness of our amazing little charity that honestly has a heart of gold. I also talk about the importance and desperate need for late effects clinics nationwide as feel this is becoming a real issue for our patients – not being able to access proper after care with all the side effects they are left with. Again, I feel it is about educating many health professionals, not only GPs and Primary Care but those in the Head and Neck Cancer Departments too.

'The MCF is a small charity with a big heart and a team that is passionate about promoting mouth cancer awareness.'

and neck cancer groups, but I had in mind the sort of group I wanted to build. Elizabeth gave me free reign on the group (for which I am incredibly grateful) after seeing my own personal page and the awareness I posted about regularly. I invited all the head and neck cancer friends and professionals I had befriended over the past six years and gradually built the group up. I would share my personal story with pictures and videos and encourage others to share theirs in a safe space where we could all be open and honest. I wanted to make sure I engaged with every single person who posted a query or their frustrations, because I understood what it was like to be 'invisible', 'unheard' or just lonely at times and I wanted every member to feel listened to always. I try to listen to the needs of the members and the group keeps evolving depending on the needs. More from this platform are joining our weekly Zooms for that extra support.

Personally, since having to leave my job in education in January, I have been incredibly busy. I have been working on improving care for our patients, especially with the late effects of treatment, and in doing this have been encountering various professionals within the head and neck cancer roles in hospitals. I have been inviting these professionals to join our Facebook group to not only see the issues that our patients and family members are encountering, but to offer advice and signpost these patients when necessary. These professionals are therapeutic radiographers and speech therapists who are willing to help. It is incredibly important that we have all these professionals willing to assist our

need connections with other patients to know that what is going on with them is normal. I recognise how important this is for us all and this is why support is incredibly necessary. I try and raise awareness of the MCF and I hope it will grow because it is a charity that is all about the patients and family members. It is a charity that isn't trying to compete with others and all the ambassadors are volunteers.

Since I have been involved with the private Facebook group, it has been growing incredibly fast, which in one respect is sad that there are so many people being diagnosed and struggling, but is wonderful in the respect that we are able to offer them a very safe space to talk about everything they need to. This type of platform wasn't around when I was diagnosed and although I had support, I didn't have the support from people who had lived experience of this journey and that is incredibly important. It is good to have varying types of support which the MCF definitely have through the helpline which is manned by Ali Lowe; the Zoom support which Joss and I co-host together; and the Facebook group which I man for the charity. I am copied into emails and can reply to whoever needs the extra support or phone them if that is their preference (although being speech impaired myself, it isn't always an ideal method of communication for me.)

There's lots of work going on behind the scenes within the charity with our professionals speaking at various conferences to raise awareness not only of the charity but of the issues our patients are dealing with and educating other dental professionals

What are your hopes for the charity in the future?

I would love to see the charity expand as I know that both Elizabeth and Laura are often overwhelmed by their workload. I know how busy I am just being a volunteer; it is extremely rewarding though, knowing how much support we are offering to so many patients and families worldwide. To date, writing this, near the end of August, we are currently at almost 730 members in two years.

The future and legacy of MCF

The MCF is a small charity with a big heart and a team that is passionate about promoting mouth cancer awareness. The twentieth anniversary is a milestone to reflect on how far a small charity has come raising awareness of head and neck cancer. This is also a time to reflect on how the mission and legacy of the charity has impacted so many lives and supported so many people with head and neck cancer as well as professionals in the past, present and future.

I urge you all to talk about mouth cancer and self-screening to patients; it really can be 'two minutes that can save your life'.

<https://www.mouthcancerfoundation.org/self-examination/>

Dedication

This article is dedicated to Dr Philip Lewis MBE, past president of the MCF who sadly passed away in October.

Acknowledgements

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Contact details

The charity can be contacted on:
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