

Patient voice

Thoughts on medical oxygen, COPD and enjoying life

My name is Kjartan Mogensen. I am 72 years old and a retired landscape architect. I was born in Reykjavík, the capital of Iceland. From early in life, I was always a very active outdoor person. I started skiing and fishing at the age of nine and later on I added sailing. Like most of the youngsters around me I also did a lot of bicycling, and I trained in football and handball up until the age of 18 years.

I completed my education as a landscape gardener at the age of 20 and worked as such in Iceland, Norway and Denmark.

At the age of 34 I went to the USA with my wife, and we have now been married for more than 40 years. She, as a medical doctor, went for further specialisation and I for a master's degree in landscape architecture. After 5 years in the USA, we returned to Iceland and have been living there ever since. We have three children and six grandchildren. They all live abroad, in Texas, Norway and Sweden. Suffice to say we have, through the years, travelled a number of times to these places to be with them.

I had my first serious problem with breathing in Stockholm, Sweden in 2008, at least as far as I can remember. I was there with my wife attending a conference. The hotel we stayed in was located on top of a steep hill. After walking up the hill with our luggage and carrying the suitcases up to the second floor I basically fell on the bed. It was the worst case of shortness of breath I have ever had. My wife thought that I had a heart attack and wanted to call an ambulance, but I refused and slowly the

breathing got easier, I felt better and was able to move about again.

When I came back to Iceland, I went to a lung specialist and was diagnosed with COPD. I had been smoking since the age of 17 and had tried to stop many times. Once I succeeded for 2 years, and at other times for a shorter period. I tried all kinds of methods, but nothing worked. It was not until 3–4 years after I was diagnosed that I was able to stop smoking.

I was admitted at a rehabilitation centre called Reykjalundur in August 2015. I had previously asked for referral to Reykjalundur, but my condition was not considered to be serious enough at that time. I stayed at the rehab centre for 6 weeks and for me it was a very good and informative time. I started using medical oxygen in the rehab centre and ever since thereafter. At first just during the day but fairly soon after also during the night. Today, I am totally dependent on medical oxygen. A year later I was admitted again to Reykjalundur and stayed there for 3 weeks.

I joined the Icelandic Lung Association (Samtök lungnasjúklinga) in 2015, and in 2018 I was elected chairman of the association for the year 2018–2019.

After my inpatient admissions at the rehabilitation centre I have continued to use their facilities. I exercise there with oxygen four times a week; twice in a swimming pool and twice in the gym under supervision of a certified physiotherapist. I see the same lung specialist every 3 months and I also have access to a pulmonary outpatient clinic if needed.

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A patient with COPD offers a valuable insight into how using medical oxygen changes a person's daily life, and how important it is to continue to socialise, keep active, and enjoy life as much as possible <http://bit.ly/2RA8tuh>



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Figure 1 *Kjartan fishing for Arctic char whilst wearing an oxygen tank.*



Figure 2 *a) Kjartan (far right) eating dinner with his wife and friends. b) Kjartan sitting at home on the porch.*

So how has COPD changed my life?

First let me say that everything has slowed down, and I must constantly think of saving energy while moving about. Taking a quick shower is out, running for the bus is out, there simply is no running. Skiing and sailing are out because of the windchill factor. I still do a little bit of fishing (figure 1) and I occasionally bike on my electrical bike on a warm summer day. Travelling by plane is becoming more bothersome than before. Getting a wheelchair in airports is usually not a problem, but I have to rely on getting oxygen onboard an aeroplane and not many airlines provide that kind of service and those that do charge a lot. The cost can even be close to the same amount as the ticket itself. This can be very frustrating, living on an island, being retired and having a lot of time but with all the children and grandchildren out of reach unless visiting by plane.

Today I am much more aware of smells than I was before. For example, going to a restaurant can lose its charm because of the smell from the kitchen, or if someone at the next table is wearing a lot of a certain perfume or aftershave.

Access to public and private spaces can be problematic, walking long hallways and having to use stairs as opposed to lifts.

Aside from the negative things mentioned above I feel quite content with my life. I have had a good and productive life as a professional and as an outdoor person. A wonderful wife, healthy children with good spouses and lovely grandchildren and instead of going abroad for a visit, now they more often come to visit us.

We have a number of good friends. We might not hold as many dinner parties as we used to, maybe age also has something to do with that, but we still do have some good ones (figure 2). We enjoy occasionally going to the theatre, the opera and seeing a good movie.

I am aware that a lot of people that use medical oxygen are shy to be seen with portable oxygen concentrators. I can understand that, but they have to change their mind if they want to go on meeting friends, go shopping or do whatever they used to do. One has to find a way to do things with the capacity one has. Also, and very importantly, when travelling out of your home and having to use medical oxygen it is necessary to have plans B and C. The batteries for the portable oxygen concentrators can run dry, bring an extra one, the chargers can malfunction, bring an extra one. The oxygen flasks can run dry, where can one get a refill or a new flask? Things can go wrong, who will fix it?

For the healthcare professionals my feeling is that they focus too much on the “whys” and not enough on how complicated the treatment for COPD can be. Little is said about how having a COPD patient in the family changes the families dynamic and how the family should react. And to complicate the treatment is the fact that each patient is unique and should be treated as such. The solution could be patient/family and the healthcare professionals working closer together.

My final words are that it is important to learn your limitations, be selective in what you do and use your energy accordingly. But most important of all, go out of the house and mingle. Participate in everyday life and live your life to the fullest, you only have one.

Kjartan Mogensen works with the Icelandic Lung Association (Samtök lungnasjúklinga), which is a member of the European Lung Foundation (ELF)'s Patient Organisation Network.

ELF was founded by the European Respiratory Society, with the aim of bringing together patients, the public and respiratory professionals to positively influence respiratory medicine. ELF is dedicated to lung health throughout Europe and draws together the leading European medical experts to provide patient information and raise public awareness about lung disease.

Affiliations

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