# THE PRICE ONLIFE

## LAUNCHING A £200,000 FUNDRAISING CAMPAIGN TO SAVE MY LIFE

MO@MOHAQUE.COM

WWW.MOHAQUE.COM

# INTRODUCTION



The sheer thought of fundraising, to give myself a chance to live, filled me with dread. It was the last thing I wanted to do, and if it wasn't for my friends and family supporting me, I know for a fact I wouldn't be here writing these words.

I chose life; I chose to stay, as I nervously said yes to fundraising.

With the love and support of thousands of people, many of whom I will never personally know or meet, I was able to raise £190,000. This allowed me access to lifesaving treatment, and in the process reduce and stabilise my cancer.

In this document, I will be sharing my fundraising journey and cover what we did. I went through the emotions and questions I faced in the build-up of fundraising and then share the processes involved. I hope that this offers a potential framework for you, or someone you know, wanting to begin a campaign of your own.

When people hear that I raised over £190,000 for my cancer treatment, I'm usually faced with a look of surprise and astonishment, and the question; 'How did you do that?' is the first that comes up.

When I look back, I am humbled, grateful, and overwhelmed with the love, support, and compassion that came my way. I repeat I am lucky to be here writing these words. The truth is it wasn't me on my own, and there is no simple answer. We didn't have a strategy, other than a bunch of actions which gained momentum and captured the hearts of many people resulting in an incredible response. We learnt along the way, and I'm offering this learning to you.

I wish you the very best if you are on a similar journey which at times feels very lonely, but I want you to know that there is so much love out there. For me deciding to fundraise was one of the toughest decisions of my life, but by being visible and vulnerable, and by learning to ask for help, I am alive sharing these words.

### BACKGROUND

In December 2014, aged 31, I was diagnosed with advanced colon cancer also known as bowel cancer. I was given a 'small chance of success' as I began treatment with chemotherapy. In the duration of one year, I went on to have 18 cycles of chemotherapy and a major operation to remove my colon and a part of my stomach. The entire year included brutal side-effects with various scares along the way including a blood clot in the lungs. So in December 2015, when I heard the words; 'there's nothing else the NHS can do for you,' my days were practically numbered.

I share my full story in my book 'Choosing To Stay: How Cancer Gave Me My Life Back,' in which I documented how I navigated from shock after shock as well as the continuous bad news. I also shared the deep meaning I found in my life while appreciating all the little things life has to offer, as well as the several life lessons I have learned along the way. You can find more information about this book at mohaque.com/book

After my diagnosis I questioned everything, and with the situation, very desperate a year after, I carried on asking. I asked my doctors about new breakthrough treatments, and they said I would be a good candidate for an immunotherapy drug. The only problem was that it wasn't available on the NHS, and when I asked how much it would cost privately, I was told I needed to be a millionaire to afford it.

#### **EXPLORING OPTIONS**

Fundraising was never an option I gave thought to initially. I looked for alternative ways to access the drugs. I tried to get onto clinical trials for the immunotherapy, but I sadly didn't qualify for any. My doctors applied to the NHS for an Independent Funding Request, but this was agonisingly denied. I applied to the drug companies for compassionate use, but these were rejected as well. I spoke to doctors from across the US to doctors in India, but the price was still extremely high. Treatment abroad wasn't feasible as costs were going to be more than the UK, especially if I was to add flight, accommodation, and on going health costs.

#### **FUNDRAISING AN OPTION**

"Fundraise? You what?" was my reaction to when my friend Ruhel suggested it as an idea. He asked why I wasn't getting the immunotherapy treatment, and the only answer I could give him was the cost. All I knew was that I needed to be 'a millionaire', which I wasn't.

"Let's Fundraise! Even if we raise £5000, we'll be doing something, let's do something", Ruhel insisted.

Fundraising was the last thing I wanted to do. But Ruhel persisted and decided to meet with me one afternoon in March 2016. I shared my personal vision with him, of creating the School of Hope; a place for orphans and street kids in undeveloped countries to discover their talents and have a chance in life. I suggested fundraising for this cause instead. He point blank said; "No, I don't care about your vision, I care about you. If we can help keep you alive, your vision becomes stronger."

I wasn't ready to fundraise for myself. Ruhel respected that and said that whenever I was ready, he'd be there to help in every way possible. It was very comforting to know someone cared so much.

#### THE COST

Needing approximately £200,000 for a year of treatment I began questioning the price on life. I had a few answers I had to find for myself, and with a 2 week spiritual trip planned for Makkah in Saudi Arabia, I would have plenty of time for soul-searching. During the trip, I asked my Sheikh about his opinion on the fundraising, and after quizzing me about the drugs and doctors' opinion, his answer was a simple, "You have a duty to seek treatment; if that means fundraising then I will help you."

When I came back to London in April 2016, we had received the NHS decision on the funding request, which was a devastating 'No.' Fundraising was now looking like a real possibility.

Although I still wasn't ready to fundraise.

#### THE LAST RESORT

Being advised, I had a 'duty to seek treatment,' fundraising was only going to be the very last resort.

I went to see my MP Keir Starmer seeking a political route. He took on my case immediately, but it would be a back and forth process liaising with the hospital, the NHS and the Department for Health for getting clarification about the reasoning and initiating an appeal process. This was always going to be a long process, with me not having the time, quite literally.

Meanwhile, my tumours continued to grow and were showing signs of it spreading into other areas.

I was resigned to saying; 'yes, let's fundraise.'

### PSYCHOLOGY: THE INNER WORK

Before any fundraising could begin, I had to do the inner work. It was an emotional time with questions around 'the price on life' being prevalent. I agonised as I went to bed each night.

Some of the questions I had to ask myself:

- ✓ Am I worthy?
- ✓ Do I deserve to live?
- ✓ Do I believe it's possible to do?
- ✓ Can I ask for help?
- ✓ Who can I ask?
- ✓ What was help at this level, asking for money?
- ✓ Can I accept the help?
- ✓ Do I say yes to life?
- ✓ Do I choose to stay?

I spoke to my mentors and trusted friends about the questions above, exploring my doubts and my fears.

I thought of reasons to stay alive. I thought of my vision. I remembered Ruhel's words; 'If we can keep you alive, your vision becomes bigger.'

I pondered on the thought of dying, and my family living on with the question; 'Would he still be alive if he was given the medication?'

I flashed through my life, from being a kid to being an adult. I was always of service to others. I'd go round to my neighbours at any time of the day or night, to fix boilers, to re-tune TV Ariel's, to solve computer problems, to water plants. I would continually go the extra mile at work: to help students, to help colleagues. I became aware that it was time to be of service to myself.

I became aware that it was my ego and pride I had to put aside.

I then affirmed; "I am enough, I am worthy, I deserve to live."

Deciding to fundraise was a very vulnerable thing to do, and I was blessed with the support of family and friends.

I nervously went back to Ruhel. The first thing he did was arrange a small meeting in his house to get a plan of action. The campaign developed organically, and we learned through trial and error.

- What are your fears about fundraising?
- What are the conversations that are taking place in your head?
- Who can you speak to about these concerns?
- What is your vision?
- What are your reasons for staying alive?

It wasn't a linear process at all, but we just did the footwork. Here is what I believed helped my cause.

#### **A CORE TEAM**

What was so important was to have a support network. Everyone is busy with their own lives, work, and family so it was important to have some people who I could talk to and rely on for different things.

- ✓ A few creative people to bounce fundraising ideas
- ✓ A few people with practical and logistical skills
- Some people with whom I could just pick up the phone and vent my frustration and anger
- ✓ People who could attend and support me at meetings/events
- Who is on your team?
- What skills/resources do you have?
- What skills/resources do you need?

#### A WIDER SUPPORT TEAM

I was overwhelmed with the love and support from various people. Many of whom I didn't know personally. These people became my supporters and ambassadors. They became emotionally invested in my cause, continuously finding ways to spread the word.

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They would share my updates with their friends and families, they would collect donations, and they would send encouraging messages.

If I were to start the campaign from the beginning; knowing what I now know, I would make a list of everyone I know and prepare them for the campaign launch.

I would give them different ways to support and help, and suggest ways to make requests to their respective network.

For example can they?

- 1) Make a donation
- 2) Share the campaign link on Facebook and other social media platforms, together with some words of encouragement including relevant #Hashtags (I talk about hashtags later).
- 3) Further the campaign through any connections they have with the press or influential people
- 4) Make individual phone calls in their network to support the campaign
- 5) Think of any other ways to help?
- Make a list of everyone you know together with some you don't. This can include:
  - Family
  - Friends
  - Colleagues
  - Members of your community, e.g. Councillors, MPs, business owners
- Make contact with them and share your intention
- Ask if they can help, making suggestions of how they can
- Share specific ideas you might have
- Keep them updated as you go

#### A CAMPAIGN IDENTITY/BRAND

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The goal or vision was very clear: Raise £200,000 to help save a life.

There was an elephant in the room at the target figure. How do you go from a bunch of guys in a sitting room talking about fundraising to then actually achieving the target?

I refer back to the inner work I did at the beginning. I knew it was a long shot and going to be difficult, but I believed that it was within the realms of possibility.

It was important to create a brand around this goal. By brand, I'm not talking about a logo. Instead, the thinking was around what could we do to make the campaign easy to remember and simple to engage with.

What keywords and phrases could we would use to make it easy for people to connect and engage with the campaign?

It might sound disconcerting talking in marketing terms for such a cause, but looking at my fundraising as 'a campaign' was very important. I knew I had to incorporate these principles where possible using all my previous experience of organising and marketing events. Before cancer, I worked in Student Development, helping students become leaders. Through the process, I was involved in various events.

Getting someone on your team who has marketing and campaigning skills will be very helpful.

We wanted to allow the maximum number of people to remember the name of the campaign, and easily search for details online if they wanted to learn more or contribute. Therefore the name of the campaign became crucial, it needed to be easy to say and spell, and be memorable. If anyone heard of my campaign, I wanted them to make use of keywords that could be easily searched and found online.

The campaign name we went with was: "Keeping Hope" which really summed up what we were doing. All we had left was hope.

We had to check the crowd funding platform to see if the name was available.

Some of the slogans we used also doubled up as hashtags for social media.

#KeepingHopeforMo

#SayingYesToLife

#### #TeamMo

Hashtags are words you choose to tie up with a conversation on social media, in this case a campaign and have this symbol '#' in front. Going online onto a social media site and typing in your hashtag words will list all the other people posting updates. Some campaign hashtags can go viral giving wider exposure.

When we promoted the campaign anyone could go into:

- Google and search 'JustGiving Keeping Hope'
- Facebook and search 'Keeping Hope For Mo'
- Directly go to the website that was built for me for my campaign to either donate, find my social media pages or more information.

#### YOU CAN VIEW MY FUNDRAISING PAGE HERE:

https://www.justgiving.com/crowdfunding/keepinghope1

#### **CROWDFUNDING PLATFORM**

I needed a way for people to donate easily and through a trusted source. There were several crowdfunding sites available with different pros and cons. Some platforms charged a fee for every donation received, while others were free. Some would release the funds once the campaign period was over while others would release funds sooner. Some insisted on having an end date to the campaign to encourage people to focus on a deadline, while others were open-ended.

I went with JustGiving, who did charge a fee. I chose them because the few people I sampled had previously donated through them. JustGiving also came with a recognisable brand which was something I felt was an advantage over the others.

There are pros and cons to whichever platform you go for, and you should always check the latest features before deciding who to go with.

#### **SOCIAL MEDIA TOOLS**

Social media is a very effective way to keep people engaged and updated with the campaign, as well as finding new people to hear your story. Crucially most of the features are free to use. My campaign page was shared hundreds of times, in fact possibly thousands of times by other people. When other people share your page, it really helps if they say or write a few words of support together with the share.

A Facebook page for your campaign: to keep people updated on the campaign, share photos from any events, medical procedures being carried out and health updates. This really allows for others to see the campaign in real time and feel part of it. People can literally be part of the journey.

**Twitter:** is great to reach different audiences. Using hashtags can allow people to follow conversations and the campaign. It is also a useful way to find journalists and for journalists to find you. I had a few journalists find me on twitter following relevant news stories, around cancer and breakthrough drugs and contacted me for interviews. These then led to published articles.

YouTube: it is possible to do videos on Facebook, but it is also a good idea to get recordings uploaded to YouTube as well. The more places you put your story and campaign the more chances you allow others to hear you and contribute. It isn't always about the number of views, and I believe in the principle 'one is better than none.' You have no idea who will see the video and what may happen as a result. Be sure to use keywords in the description space, as it will show up in search results. One of my videos didn't have many views at all but was picked up by a researcher for a production company that led to a meeting.

**Instagram**: is a way to catalogue your photos and use hashtags. Remember different people use different social media tools, and so what you post on Facebook may not be seen by others in your community. Taking a few mins to share the same photo or video on a different platform gives more people a chance to follow your update and engage with you.

People will donate more than once as your campaign progresses, and as you provide updates, they too can share with their network to encourage further contributions.

I was never natural at posting on social media platforms, but when the campaign went live I would find opportunities to stop in the streets, and take a photo or record a video. It could have been on route to the hospital, or even at the hospital for a check-up. Or it could have been at a meeting or fundraising activity. I would then share the update on the appropriate social media platform. This sharing may sound daunting, but it definitely helps build momentum and brings energy to your campaign.

Before the fundraising, the thought of taking selfies in the streets would make me cringe, but it's something I became more and more accustomed to letting the world know I was Keeping Hope.

I was willing to be seen and be heard. I utilised the different tools available. If you are new to social media you might want to put a request out for people who are to help you get started.

It will be useful to have some volunteers on your team who can be given access to share on your behalf with admin rights.

The tools are forever evolving with features, and there will be new platforms that emerge, so it's important to use whatever is available.

If you want to learn how to use these tools you can go to youtube.com and search for what you need help with. There is sure to be a video explaining the most recent version and updates.

Most of them are free to download and use. There are advanced features which allow for paid advertising, but they aren't essential.

#### **PUBLICITY MATERIALS**

It is useful to have flyers, or simple strips of A4 cut out with the details of how people can donate.

These can be very cost effective. We were able to fit several lines incorporating the JustGiving link in a word document with the crowdfunding link and Facebook page details printed out on a single page of A4. We made photocopies and cut them out into little strips. It was a very simple, cheap and effective way of handing out the details.

If you are attending an event, it is useful to have flyers. Again it doesn't have to be fancy; canva.com is a great resource to design your own versions for free. If you can get a print company to print for free, or ask someone to sponsor the cost that can help save you money. If you don't ask, you will never know.

Remember to include the basic info on to the promotional material:

How to donate: link to crowdfunding

How to get in touch: email/telephone

The social media account links

If you are promoting an event, you will need the event details: e.g.

Where: venue address

What: the event/activity details

When: date and time,

Ticket info: how to purchase and price

Any other relevant info such as a keynote speaker, or performance

#### **TELLING THE STORY**

This will not be the usual everyday conversational topic people are used to, so finding various ways to tell the story is crucial, both written and spoken.

Sometimes you will meet people for the first time, and saying you are raising money for your own cancer treatment will be overwhelming to hear. I've had people begin to cry because they have a story that is close to home whereby someone they love is going through their own cancer story or has sadly died.

Nevertheless, being clear, authentic, with a heartfelt request is what you need to do.

Sometimes I was invited to an event and be told you have 1 minute to make your appeal, other times I was told you have as long as you need. On one occasion I was told I'd have 10 minutes but then due to the event overrunning, my time had reduced to 30 seconds.

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Therefore be prepared for various levels of time to speak, and make sure you have the key points, and how people can donate.

Mention web links, and social media pages to follow e.g. the Facebook page,

If you have flyers, have these available for distribution which should have ways to donate and help.

Depending on the crowdfunding site you use, you'll have space to write your story, the reason why you are needing to fundraise. This area may have a word count restriction. What you write needs to be clear, authentic, have emotion and be written in such a way that answers any question people may have.

You will have strangers who will go to the site and read the story for the first time, therefore will play a part in the decision making to contribute.

Most platforms also have the ability to upload videos, so you might want to film a spoken version. This can be done on any smartphone.

The page could be written by you, or by a family member or even a friend, someone who will be running the campaign. For mine, I was central to the campaign, and I had various people helping in different ways.

After you have written your story and made a video, it will be good to show a few of your trusted team to get feedback.

#### OFFICIAL LETTERS OF SUPPORT/ENDORSEMENT

After my campaign began, the donations were incredibly coming in. There were messages of support from strangers as well as loved ones.

There were some questions from people asking for clarification. The fact that the NHS didn't provide this treatment was a new phenomenon for a lot of people and brought up some questions;

'Are you an illegal immigrant?

Are you on a student visa?

Why won't the NHS pay for it?'

One suggestion was to get a letter from the hospital. As such I emailed my nurse asking if she could ask my oncologist to write me a letter. I was a bit cheeky in my request as

I asked if I could collect it the following day at his clinic. Incredibly my nurse replied with a 'yes'. I went to the clinic the next day and had the letter in my hand.

I was able to upload the letter on my JustGiving page as well as use it when I approached other organisations for their help. This provided more credibility as it eased people's concerns as to whether I was a genuine patient.

Other ways I was able to get endorsement was through my local councillors and MP. I got in touch with them by making phone calls and turning up to open meetings. They immediately offered their support. They attended local community fundraising event, which allowed for photo opportunities and for others to associate additional credibility for the campaign.

It is also an idea to contact other charities to see if there is anything they can do to help. One charity gave me a booklet of fundraising ideas.

Going and asking for support from local business, whether that's by having a collection pot or another form of contribution. My local pharmacy had a collection box; another business sponsored marketing materials to distribute, while another built me a website.

Do not be afraid to ask, the worst you will hear is a no. And at times you might not get an immediate reply to an email or a message. Sometimes replies come weeks later. There's no point dwelling on why someone isn't responding or declines to support, its best to focus on those who are happy to help while looking for new ways of expanding the campaign.

#### **GETTING THE MEDIA INVOLVED**

The local media are a great way of getting the story out. Sometimes it's looking for the health editor details online, and then dropping them an email or a phone call. Journalists are busy and are always under pressing deadlines, so you might need to try a few times before you actually speak to someone. Ask your network of friends and family if they know anyone in the local paper or radio teams who can put you in direct touch.

Be prepared for the calls with the journalists. They would want to know more about you, the condition, and the campaign. Have this written down in a timeline so that it can help the flow of the call.

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Have a collection of photos ready to send. I had a mixture of hospital photos as well as ones taken from different campaign activities.

It is also useful to have a press release written. I found templates online with how to structure one and then filled in the appropriate sections. I emailed various publications asking if they'd like to cover my story, and some of them came back with a yes.

Whatever press you get, be sure to share it with your team and followers. It will give everyone encouragement that the campaign is getting further coverage and reach.

Whether it's online or in a written publication, take a screenshot or a photo of the article and share across the various social media platforms using relevant hashtags. Remember to include a call to action with donation links included in your posts.

After it became clear the political route wasn't going anywhere, my MP decided to submit his letter to the Department of Health as a press release. This was picked up by a London paper the Evening Standard, who covered my story. ITV London also picked up the story and arranged a day to film at the hospital together with me, Ruhel and oncologist. The piece was a couple of minutes long and broadcast on the 6 pm London News. I made a recording and shared it on my social media channel, which was subsequently viewed by further 2000 people.

Getting media coverage may not necessarily result in making the campaign go viral, but it will help you in building credibility and gaining visibility.

#### **BLOG OR WEBSITE**

Now you might be thinking that if you are already sharing updates on all the other platforms, is it necessary to have a blog or website. The truth is, it isn't crucial.

But if someone on your team can help set one up it can be useful.

There will be days when emotions are charged, and being honest about your feelings can be powerful. Blog sites can be free and allow you to write, video or upload photos. You can use it as an archive of everything you are doing campaign-related.

There are several free blog sites and website builders available which are simple to use.

#### **EVENTS AND ACTIVITIES**

Carrying out fundraising activities in addition to online promotion is very helpful. And it's important to know you don't need to do them all yourself. Encourage your support network to carry out fundraising initiatives of their own. Make a list of possible activities:

Cake sales, movie nights, dinners, entertainment shows, stalls at community events and festivals, shop counters, sports events. Many organisations hold dinners throughout the year, perhaps your fundraising can be the chosen campaign or charitable cause. Ask members of your team to make enquiries.

Your mind might be quick to question whether £29 raised from an office cake sale will make a difference in the quest for the overall target such as £200,000 in my case, but believe me, it all adds up. The cliche every penny counts is so very true. Every £ collected adds to the receiving energy field. The more you are able to receive with gratitude, the more you are opening up to receive.

I had friends and families in various parts of the world running activities and collections of their own. They knew my story and went out to their network collecting funds.

Schools, colleges, universities, offices, places where people run several fundraising events. Friends and even complete strangers cycled and ran long distances for me. It was unbelievable.

The more people you are prepared to connect with and ask the question, the more possibilities you will be opening up. The 6 degrees of separation theory is very powerful; you will know someone, who will know someone else. There were two people in New Zealand who picked up on my campaign; friend of a friend, of a friend to do a 50-day cycle trek across New Zealand raising almost £5000. This shows the love and compassion that exists within humanity.

#### **COMPANIES**

I previously mentioned talking to local businesses. I strongly suggest contacting businesses or ask friends who work in businesses to contribute or provide sponsorship.

Can they send around your appeal to their staff?

Can they offer items for auctions?

Can offer sponsorship for an activity or event?

Maybe they can sponsor print publicity or campaign materials such as T-shirts or banners? These are just some ideas; talk with your team to explore which companies you can approach.

#### **NICHE MEDIA**

Use whatever contacts you have, and be ready to ask without limit. I may not have had direct contact with people in charge of certain UK based Bangladeshi TV channels, but family and friends, and people in my network did. They asked for help on my behalf.

The first TV channel I went on was Sky 849, TV One, and the show was to raise awareness amongst the Bangladeshi community in the UK. They didn't have any fundraising telephone lines set up, but they did advertise my crowdfunding link. The show was on a Sunday night scheduled for 90 mins from 10.30pm to midnight. The calls into the studio were nonstop that the show went on for an extra hour until 1 am.

The message was clear, so many people wanted to help. Whether it was a small amount or a large amount, they wanted to be part of the campaign.

We had two further TV appearances for fundraising Bangla TV, Sky 879 and Channel S Sky 814. For these respective appeals, we had registered charities supporting us so that we could take live donations over the phone lines.

#### **MOSQUES**

I was invited to speak at several mosques to make a short 1-minute appeal before prayer time. I would have friends and family at the doors with buckets to collect and flyers ready to hand out. I was also present and available to answer any specific questions.

#### **COMMUNITY ORGANISATIONS**

With your team, make a list of all community organisations. Then contact them in person or drop them a call asking for a meeting. Discuss with them how can help, and suggest ways they might be able to. Ask if they can arrange a time to appeal to their members, or perhaps arrange fundraising activities.

#### **PROTECTING YOUR ENERGY**

I have mentioned some ideas you can do as part of your campaign. Don't let this limit you or overwhelm you. All you and your team can do is your best.

It is very important to look after your energy levels as well as maintaining boundaries. Having a deadly disease is draining in itself, therefore being out and about will only add to the exertion. Having a team to support you, to go and do the footwork is vitally important. There will be days you physically can't do what you want to, and on those days allow your team to go out.

#### **NEXT STEPS**

I've shared a number of questions and areas to think about. From starting with the psychological and emotional inner work, to the more practical steps of building of a team, creating a campaign identity, as well as setting up social media sites. There's a lot to do, but with a support network it is possible. The human spirit is incredible as my story proves.

It breaks my heart that we live in a world where healthcare is dependent on finances and we are required to go out and seek desperate support from family, friends, and strangers. But there is a lot of love, care and compassion out there. It is my deep desire that you have found this booklet, together with the videos on my website and YouTube channel, of value. If you want to view these you can find them at www.mohaque.com

I send you all my love,

Mo.