

Sharing my story with the media



Seeing a story in print or online can be really exciting. However, there are also a number of things to consider before choosing to work with the media.

Why do people share their story with the media?

Each person has a different and personal reason for sharing their story with the media. These might include:

- Wanting to raise awareness of this rare cancer. Many people feel that if they had known the signs and symptoms of leukaemia, they may have seen a GP sooner or felt more prepared for what was to come.
- Wanting to share an incredible element of their story. For example, they were diagnosed abroad or at an unusual age.
- In order to achieve a goal. Media stories, especially in the social media age, can grab the attention of famous people or those with decision making capabilities like MPs. For example, some families choose to share their story to find a stem cell donor or access a drug not funded on the NHS.
- To raise money to pay for treatment abroad or to pay for funerals.

Will my story be published?

Journalists looking for stories will assess how interested people will be in your story by looking for "news value". These are things that make a story more interesting and could include:

- Location (especially local newspapers)
- Age of people involved (stories about children can make people react more emotionally)
- Unusual events/coincidences/unique circumstances
- Timeliness (is leukaemia/cancer in the news already? Has it affected someone famous? Have there been recent and related NHS announcements?)
- Conflict (this is why wars often make the news, but could just be a conflict between you and the system, such as problems accessing a drug)

Essentially, being diagnosed with a leukaemia will not be enough of a 'story' on its own. You may need to think about what makes your story unusual and emphasise this when you tell the story.

In which format might my story be published?

There are several ways you could share your story. Most people still choose to share their story with newspapers, and they now also have an online versions, meaning your story can often reach millions very quickly. Radio and TV are also options too, but it can be harder to get coverage here due to limited air time. Radio and TV often come after the newspapers too, in order to debate things the public are already talking about, so you might like to go for print media first to build interest.

Here are some ways to start the process:

- Approach a local outlet to talk about your story. This will be more appealing to them if you are local to the area they cover, or something in your story happened locally.
- Approach a national organisation about your story. This is good if you would like to control which outlet publishes your story but may also limit your reach. They may also want to know why you think your are of interest to their readers in particular.
- Social media: You may choose to share your story via your own social media profile. It is a good way to reach lots of

people and very quickly, and a good way catch the attention of traditional media or online influencers.

- Work with a press agency. These are organisations that search for stories, write them up and offer them to newspapers as quick pieces for them to publish. This might be a good way to get published in several places at once with less work for you. It may also allow you to control who you send the story too, as different agencies only work with certain news outlets.

I have been asked to appear on television or radio, how is this different to written media?

If you are published in a newspaper, there is usually a length of time between you approaching them and publishing, to allow for stories to be written and checked. Radio and TV typically look for stories much quicker and usually follow up on stories in the written media.

Radio

For local radio, typically you will be asked to do a phone interview for a particular slot for example, the breakfast show or drivetime slots which is when there are lots of people listening. If you live in a town or city with a radio studio, you may get asked if you can go into the studio. Otherwise, you will be asked if you could conduct the interview down the phone. If the interview is by phone, a producer should speak to you first, before then transferring you to the presenter in the studio. Either way, they should prepare you for the interview beforehand and give you a chance to ask questions.

Television

Television outlets typically work on very short time scales, so you may be asked if you can appear within 24 hours or so. Increasingly

for shorter slots on daytime TV, you will be asked if you could appear via Skype. For some shows, they would prefer if you could join them in the studio and this typically will be in London, or possibly other large cities such as Manchester or Birmingham.

In this example, you should ask if you could claim expenses for travel to London and any potential stay. Many of the big daytime television shows will arrange this with you at the point of agreeing to appear on television. There may also be an appearance fee involved but this will be discussed before you agree to appear.

The nature of the news is that things can change and happen quite quickly and therefore, there is always the possibility that your appearance may be cancelled on the show. If cancelled, you can establish whether they are looking to rearrange or whether you are no longer needed. Don't be disheartened by this – it happens all of the time and to many celebrities or other important people too.

Can I get help with publishing my story?

You may want to consider working with a charity to share your story on their website or within their publications such as magazines. The charity may then ask if you

would be interested in making your story more public in the local or national newspapers

The advantage of working with a charity includes the following:

- The charity can liaise with the media directly for you
- If the story becomes very popular, the charity can field calls from the media for you
- They can give you advice on the types of publication that are coming forward, so you can decide who to get involved with.
- If you are looking to raise awareness of that particular charity, they can be mentioned within the article (typically at the end)

What can I control about my story when I publish it?

There are some controls you can put in place to manage your story in the media. However, there are some things that are beyond your control once they are made public.

What you have some control over:

Ask for a read back

Before agreeing to be interviewed, you can agree on terms with the person doing the interview. These terms can include being given a "read-back" of the story that they create from your interview.

During this read-back, the person doing the interview should read out the story so you can hear the details from start to finish. If you are going to be featured in an online publication, you may be able to be sent a document of the story as it is.

If you are unhappy with the content of the story, this is the point where you should insist on any changes. For the readback, it might be useful to have a family member, trusted friend or even a charity representative present to hear the call back too and to give you the confidence to say if you are unhappy.

Your read-back will most likely be the last chance you get to make amends before the story is published. Once a story is published, amending it is extremely difficult and corrections are rarely seen, especially if shared via social media.

Photographs or video

Invariably, any media type will want a photograph or video to illustrate the story.

Before you sit down to any interview, be clear in your own mind what types of photos you are happy to share with the media.

If your story is about a leukaemia diagnosis, a journalist will ask if you have any pictures you could share of yourself at that time. If you do not feel comfortable in sharing these photos, do not send them. Only send photos that you would be comfortable with complete strangers seeing. The same consideration needs to be made if you are sharing a photo of yourself with others – for example, a photo of you with your children or other half.

Once pictures have been made public, particularly online, it is incredibly difficult to retract them so be sure before you release them.

If you have filmed a video as part of your story, ensure that you have seen the video and are happy that it is a true representation of what you have said.

What you have less control over:

Where the story will appear

Once a story is published, it is very difficult to control where it appears. In this social media age, a story can also be widely shared over social media sometimes with thousands of individuals sharing the same story.

Here is an example of how a story could go further the first media outlet you contact:

Patient X talks to their local newspaper about their shock of being diagnosed with AML whilst on a family holiday in Spain. This local newspaper is owned by a larger media group which includes national newspapers. A journalist from a national newspaper reads the local newspaper and uses the content for the national newspaper's website. This story is then shared over 1,000 times on Facebook alone. After the reaction to the story, a national radio show wishes to interview Patient X and their family, and a daytime national TV show asks them to appear the next day to share their experience.

You may also have thoughts and feelings about a particular newspaper or website. If you don't want your story to appear on certain news website, you could choose to go directly to another news source. If you talk to a press agency about your story, the information will be shared amongst many outlets. You can ask who they share their stories with, but you cannot pick and choose from the outlets which an agency works with.

If you have other media outlets approaching you about your story after publication, but you would rather not appear there, you can tell them this when they approach you.

You will also have little control

about the story being shared on social media. If you are worried about friends, family or colleagues reading the story on social media platforms, we would advise not to share your story. Even if the newspaper or radio station does not put the story online, any member of the public can post about your story after reading it.

Headlines

Headlines for a story are typically written by somebody other than the journalist creating the story. This could be an editor or sub-editor. Headlines are there to create interest in a story. This means that sometimes they can seem dramatic or salacious.

Sometimes, you may be able to ask for headline approval on a story, but this may not always be possible. You may be able to advise on things that you would not want to see in a headline.

Who will share your story

As previously mentioned, once the story is public, it is open for anybody to share. It could be shared by media outlets, the general public on social media and local newspapers. Don't be shocked to see your own story shared on Facebook or other social media sites – this is par for the course nowadays.

Reaction to your story

Stories invoke different emotions in people. Often, people will comment on stories online. Our key piece of advice would be not to look at the comments. While you will have plenty of supportive messages, there will always be somebody online looking to cause trouble. These people are known as trolls. They mostly post insensitive or personal comments. One negative comment like this can overshadow thousands of positive ones so we'd advise not to read any comments at all.

If you are working with a charity and you're interested to hear what people have been saying, they may be able to put together a collection of comments together that you would like to read, sparing you any negative and unhelpful ones.

As well as simply commenting, you may receive contact from members of the public about your story. It is quite easy for people to find you on social media from just a name or a picture (see how to prepare to share below). Most of these people will want to share a supportive message, but if you receive unwanted attention, you should use the tools on the social media sites to report the messages or block the people in question from contacting you.

Search histories

If you have shared your story online, you may well be indexed on search engines. This means that if somebody searched for your name, the story would appear in search histories.

There is something known as the "Right to be forgotten". This was added to data protection law with the General Data Protection Regulation (GDPR) laws, brought into place in the EU in May 2018. Under this, you can write to Google and ask for information that is indexed about you, such as a story, to be removed from search results. Although this won't remove the information from the individual websites or social media, it will stop people finding them through Google.

Google have created a form where you can make your request to be forgotten, and you can find that here: https://www.google.com/webmasters/tools/legal-removal-request?complaint_type=rtbf&visit_id=636812691350981068-928487754&rd=1&pli=1

Will I be paid for a story?

If you go direct to an outlet, there may be payment for your story, although this is up to the organisation in question. For print media, it is more common to be

paid for magazines stories than for newspaper ones. If you are interested, you should ask if you will be paid before you agree to tell the story.

In the case of TV, if you are asked to travel for an interview you may be offered expenses to ensure that you are not left out of pocket.

Case study: Take a Break magazine

Take a Break magazine is one of the biggest women's magazines in the UK today. They offer the chance to approach the magazine directly to sell a story. The fee for a story ranges from £200 - £2,000 but is typically £3-500. The magazine collects your details via a form and if the story is of interest to them, the editorial team get in touch directly to find out more. Once a story is published, you are paid around 4-6 weeks later. Once a story is published, they hold the exclusive rights for approximately 10 days from publishing date and after this, your story is free to appear elsewhere.

What can I do to prepare for publication or a media appearance?

Privacy settings on social media

If you are working on a story with a national print publication, you will normally be told when the story will go live.

This gives you time to go through your social media privacy settings

and decide what people can see. As previously mentioned, it is easy for people to find your social media accounts from your name and your picture; once they are on your profile, they may find out information that you did not want to publish in the story. You can change your settings on Twitter, Instagram and Facebook to limit what is available to people who aren't your friends or followers.

Decide in advance what you are willing to share

Before doing any interview, write down all the things that you are comfortable in sharing. Then, write a second list of what you wouldn't want sharing.

Take this information into any interview with you. When interviewed, people may ask about certain topics. If you decline to talk about a certain topic, they may ask you in a slightly different way. Remember, you are in control of the interview and can decline to talk about any topic you wish. It is the same principle for photos or videos too.

I've inadvertently become the focus of the media and I'm getting phone calls - what do I do?

You may become the focus of the media if you or a media outlet you approached have shared something on social media and it

has gone viral. For example, you may have become the first in the world to be offered a certain type of treatment, or something that has happened to you has become particularly news worthy.

Much of our lives nowadays is public and therefore it isn't difficult for journalists to get in touch with you. Some may try to ring you. Others may send you messages via social media. Some of this can become very overwhelming. Some people may want to engage with the media in this way, but you are unsure how to handle it.

There are a few ways to deal with the messages or phone calls:

- Take a breather and think about what you want to share
- If you have received a phone call or message, you do not need to answer any questions straight away. Calmly, tell the person you'll be in touch if you wish to talk. This then gives you time to think about what you want to do.
- At this point, you could also contact a relevant charity, explain the situation and the communications department should be able to support and advise you.

If the contact is unwanted

On your mobile phone, you have the option to block phone calls if you wish. If the phone calls are from a private number, simply tell the individual that you do not wish to talk and to please refrain from ringing. On social media, you also have the option to block messages or the person who has sent the message.

If you do not wish to talk to the media, you may also want to talk to close family and friends who are linked with you on social media and express your wishes for them not to speak to the media on your behalf.

As above, a charities communication department should be able to support and advise you.

Further support and information

If you are interested in sharing your story, Leukaemia Care have a communications team who can support and advise you in the ways that you could achieve this. You can also get in touch if you need support for a story that has already gone public.

For support from the media and communications team, call 01905 755977 (Monday-Friday 9am – 5.30pm). If you need support out of these hours, we do offer

an out of hours number but this is strictly for media related enquiries; call 07957 675121.