

PATIENTS IN MEDIA AND SOCIAL MEDIA

Guide for patients and their next of kin

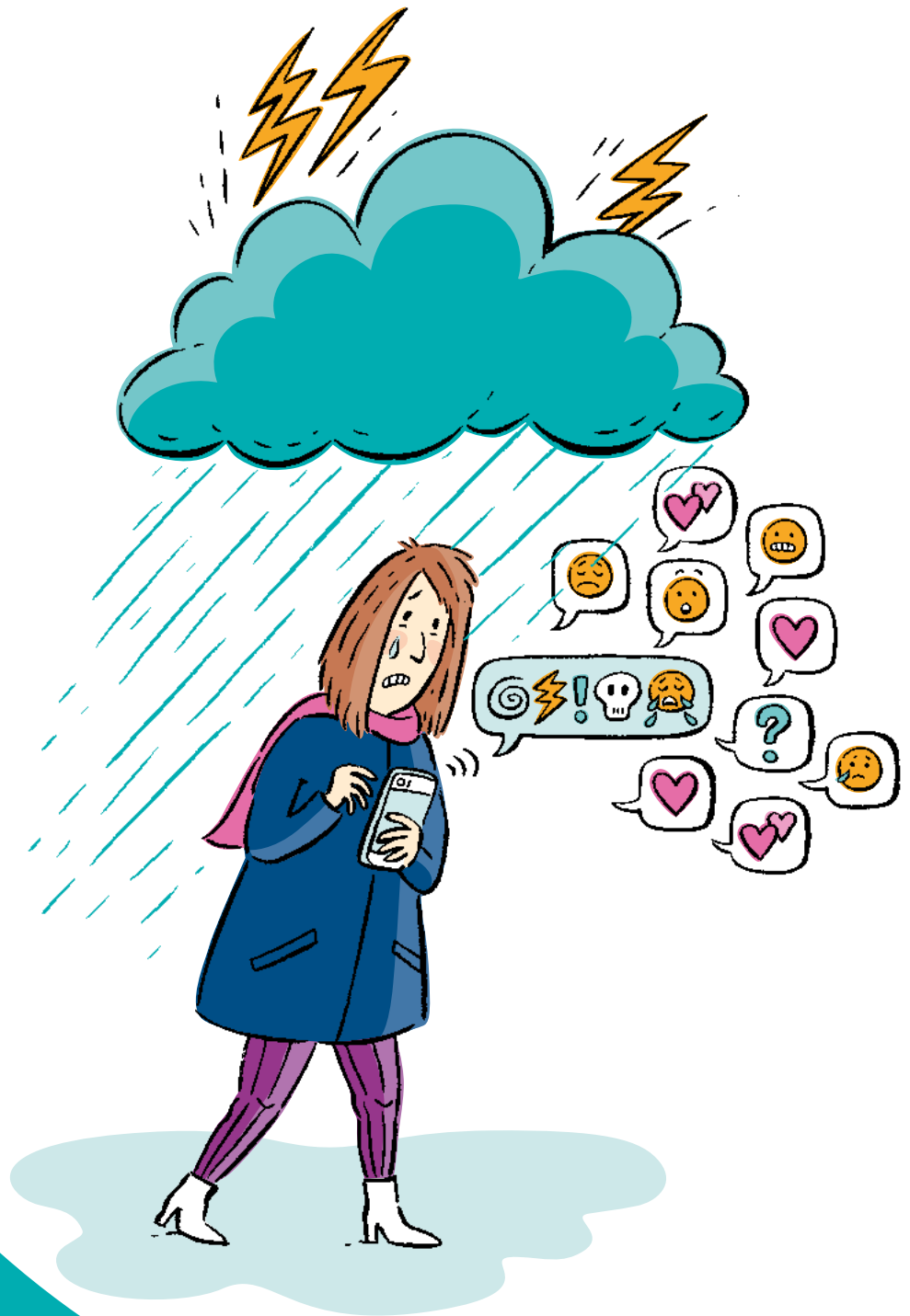
FOR THE READER

Social media channels play a key role in the daily lives of almost all of us. Social media has become an important channel of expression: we explain what we do, where we are, we ask for opinions and we interact with each other. Social media has taken over part of the role of the traditional media: today, we can all be part of the media by publishing content, such as texts and images, on our own channels.

The peer support and information received from social media and online may be of essential help when processing emotions related to illnesses or accidents. Sometimes, social media may also cause fear and conflict. Although social media channels offer an effortless way to search information and receive peer support, they also contain plenty of personal opinions or views on e.g. therapies, disguised as information.

The media is interested in patient stories. Patient interviews are important, since they help increase information on various illnesses and matters related to illness. It is recommended that you prepare for interviews beforehand and that you are aware of your own rights as an interviewee.

This guide is intended to support HUS patients and their next of kin in dealing with the media and using social media.



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CRISES ARE ALSO VISIBLE ON SOCIAL MEDIA

Various crises, loss and grief are part of our lives. Everyone must face them at some stage of their lives. Serious illness or an accident may lead to fear, confusion and grief.

Overcoming a crisis usually consists of four stages: the shock stage, the reaction stage, the processing stage and the reorientation stage.

- Behaviour in the shock stage varies from lethargy to denial or even panic.
- In the reaction stage, we are fearful and distressed, and we need to find those to blame. Social media offers a channel for expressing our negative emotions, and everyone gets their share of it: our inner circle, nurses, doctors, other patients, and we also blame ourselves.
- In the processing stage, we are already able to express our emotions verbally and begin to understand what happened. Peer support received from various channels and groups is extremely important and helps us recover.
- In the reorientation stage, we have accepted what happened as part of our lives. It is a scar we can live with. At this stage, we can offer support to others.

Social media is today's tea table. That is where we gather to find peer support and process what happened. Peer support is necessary for recovery, but during the crisis, keep a cool head when publishing texts, since emotions may be stronger than common sense at various stages of the crisis.

BE CRITICAL OF THE ADVICE YOU RECEIVE

When you talk about your illness or the illness of your next of kin on social media, you may receive not only thumbs up and peer support but also tips and advice contradicting current medical views.

Each patient has an individual course of treatment. Whatever may have worked for your acquaintance may not necessar-

ily work for you. That is why you should set certain limits and listen to healthcare professionals. When receiving treatment for an illness, many different things may help and relief, but be critical of those offering help and advice on social media. Some of those offering help also have commercial interests in mind.

Particularly for the treatment of long-term illnesses, it is better to discuss various options with your physician rather than among strangers on social media. The suggestions made might mean well, but only the staff treating you have an overview of your health.

Be critical of those offering help and advice on social media.



TAKING PHOTOS AT THE HOSPITAL

We all have the right to decide on our visibility on social media. We all also have the right to take care of our health and, at the same time, keep our privacy.

Under the law, it is permitted to take photographs in public spaces as long as personal or identifiable data are not distributed. Lobbies, waiting rooms and cafés are part of hospitals' public space. You may take photographs there, but if another patient is photographed, it is po-

lite to ask their permission for publication. Photographing other patients without their permission is prohibited. Their status as patients may be something they wish to keep secret.

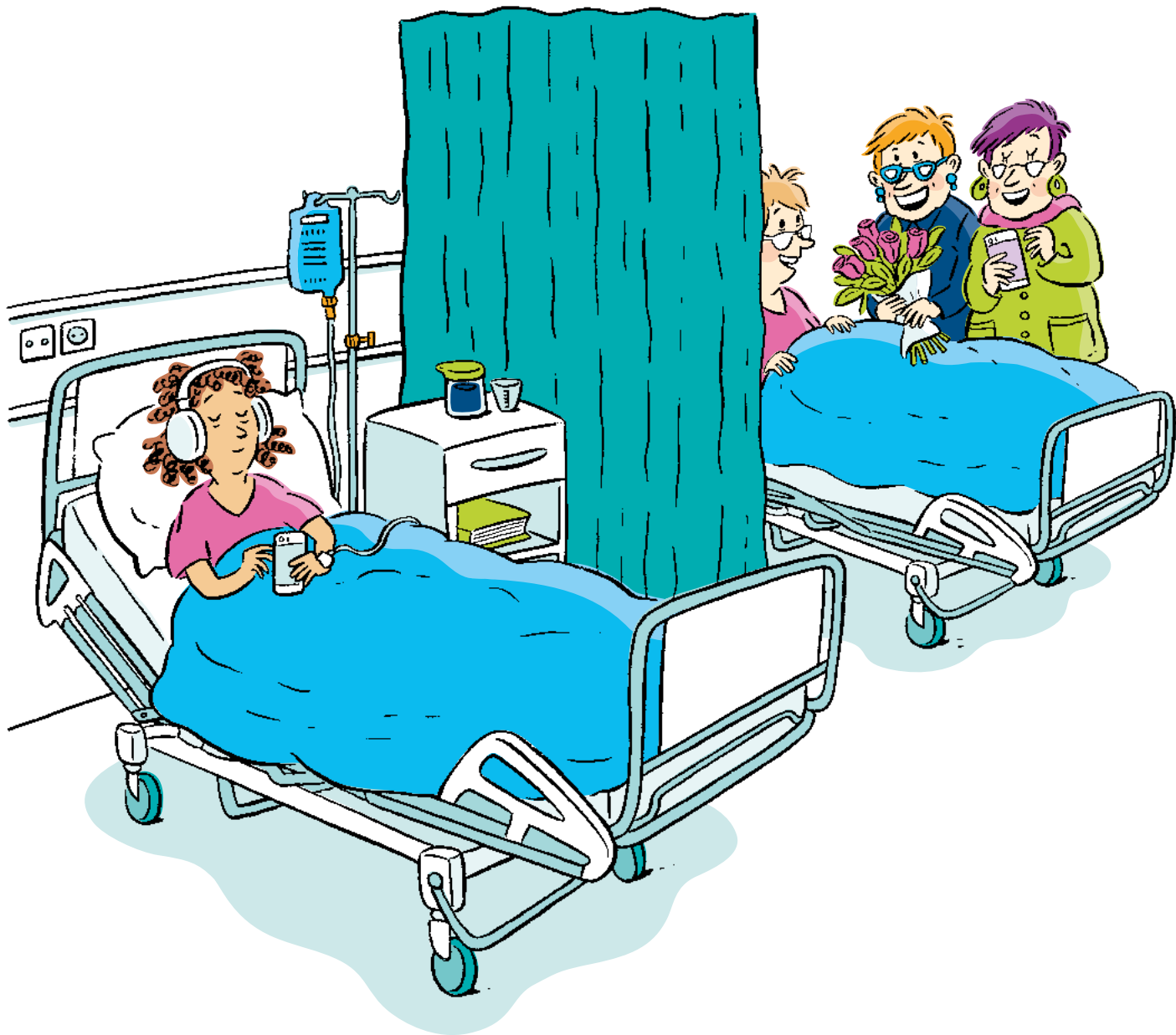
On social media, you may share nothing that may indirectly result in the violation of another person's privacy. The presence of a person in the background of a photograph taken at a hospital may as such be interpreted as the distribu-

tion of information on their private lives. Please consider what you publish.

Reception rooms, procedure rooms and patient rooms are not public spaces, and photography in these spaces may be restricted to protect the privacy of other patients or for the sake of patient safety. Before you take photographs, please discuss the matter with the staff. Please remember that you also have the right to decide that you may not be photographed.

We all have the right to our privacy.





RESPECT THE PRIVACY OF OTHER PATIENTS

Health-related matters are sensitive. At HUS, we wish to create a safe environment where patients may rely on the staff, other patients as well as visitors.

The hospital environment requires consideration for the other patients and their next of kin. As a patient or next of kin, you can ensure that you respect the privacy of all patients. The diagnoses,

treatments and symptoms of other patients or information on the people visiting them should not be divulged on social media, since they are all covered by protection of privacy.

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CHILDREN ALSO HAVE A RIGHT TO PRIVACY

We all have a right to privacy, both adults and children. As parents, we should assess the extent to which the use of social media should be kept private or public. When you publish content about your child, ensure that you know with whom you are communicating on various social media channels.

Taking their age into account, children should be able to take a stand on

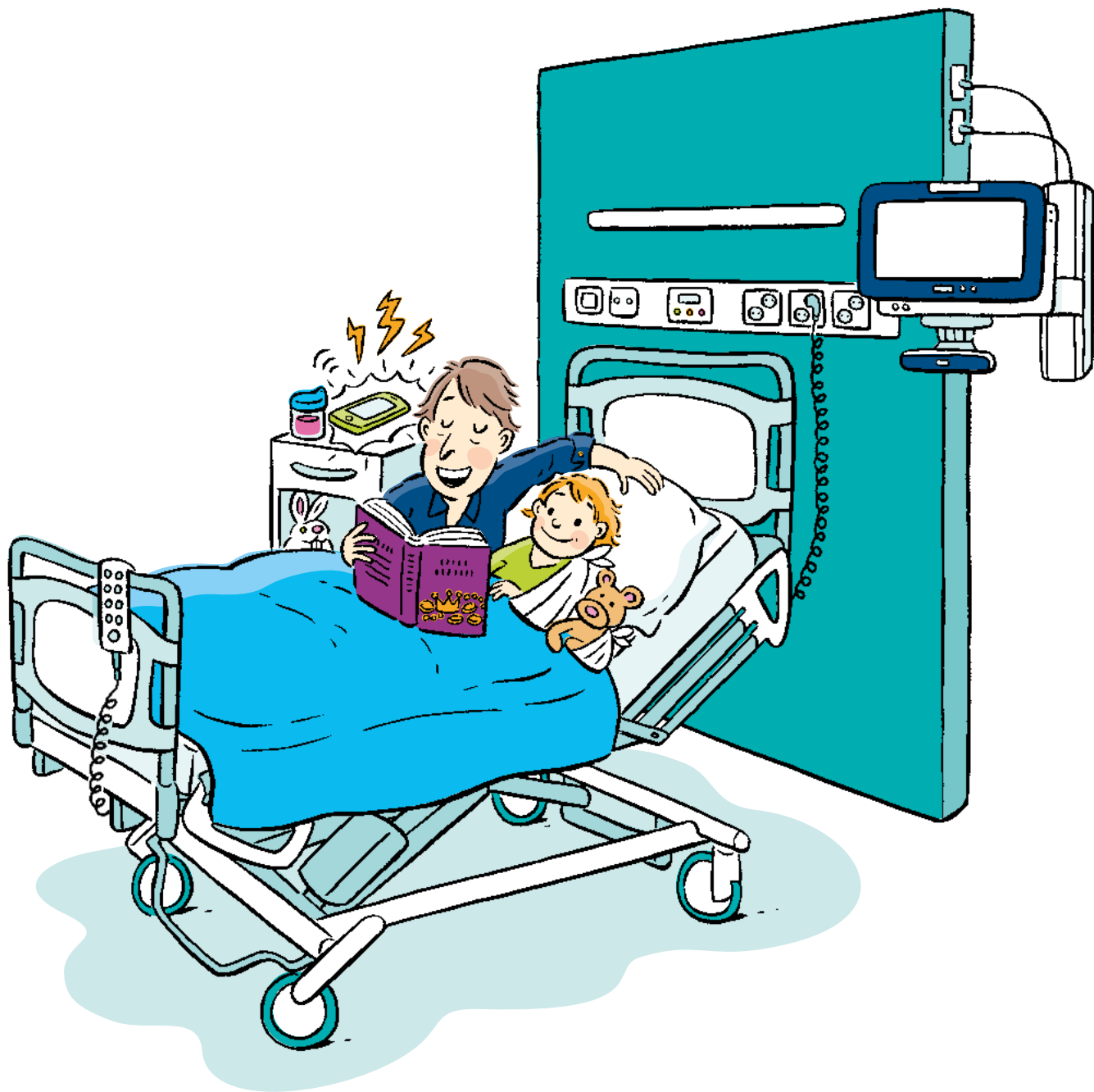
what is published about them. As small children cannot decide what you publish on them, you should consider it particularly carefully as an adult and as a parent. Photographs of other children may not be published without the consent of their parents.

Issues with social media are often related to adults neglecting the code of conduct or being ill-mannered. Adults

should be role models both on social media and outside of it. It is important to set children an example of responsible and respectful behaviour.

The hospital environment may be a frightening place for children, and they may need particular support. The attention of their parents will make children feel secure: please focus on your child instead of social media.

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ASK FOR PERMISSION BEFORE PHOTOGRAPHING STAFF

Our staff have a right to their privacy. Not all employees wish to be photographed. Be sure to always ask for permission before photographing staff. Also, ask for permission if you wish to publish a photo or video.

Please do not be offended if the staff do not wish or have the time to take pho-

tographs. They have the right to refuse taking photos.

Our staff are bound by professional confidentiality. This is why our staff will not make comments or take a stand on the treatment of individual patients on social media or elsewhere in the media. Although the patient may reveal facts in

public, our staff are bound by professional confidentiality. You should always give feedback on your treatment on the official HUS feedback channels.

**Not all employees
wish to be
photographed.**

DEAL WITH THE MEDIA ON YOUR OWN TERMS

The media is interested in stories. Genuine patient stories are used to transmit information on illnesses. In addition, reading the story of those sharing your fate in magazines may be of critical importance: you may discover a reason for your symptoms or you may learn that there are others with the same experiences.

If you end up giving an interview, you can decide yourself what you reveal. In articles, journalists may use everything you say during the interview, so consider

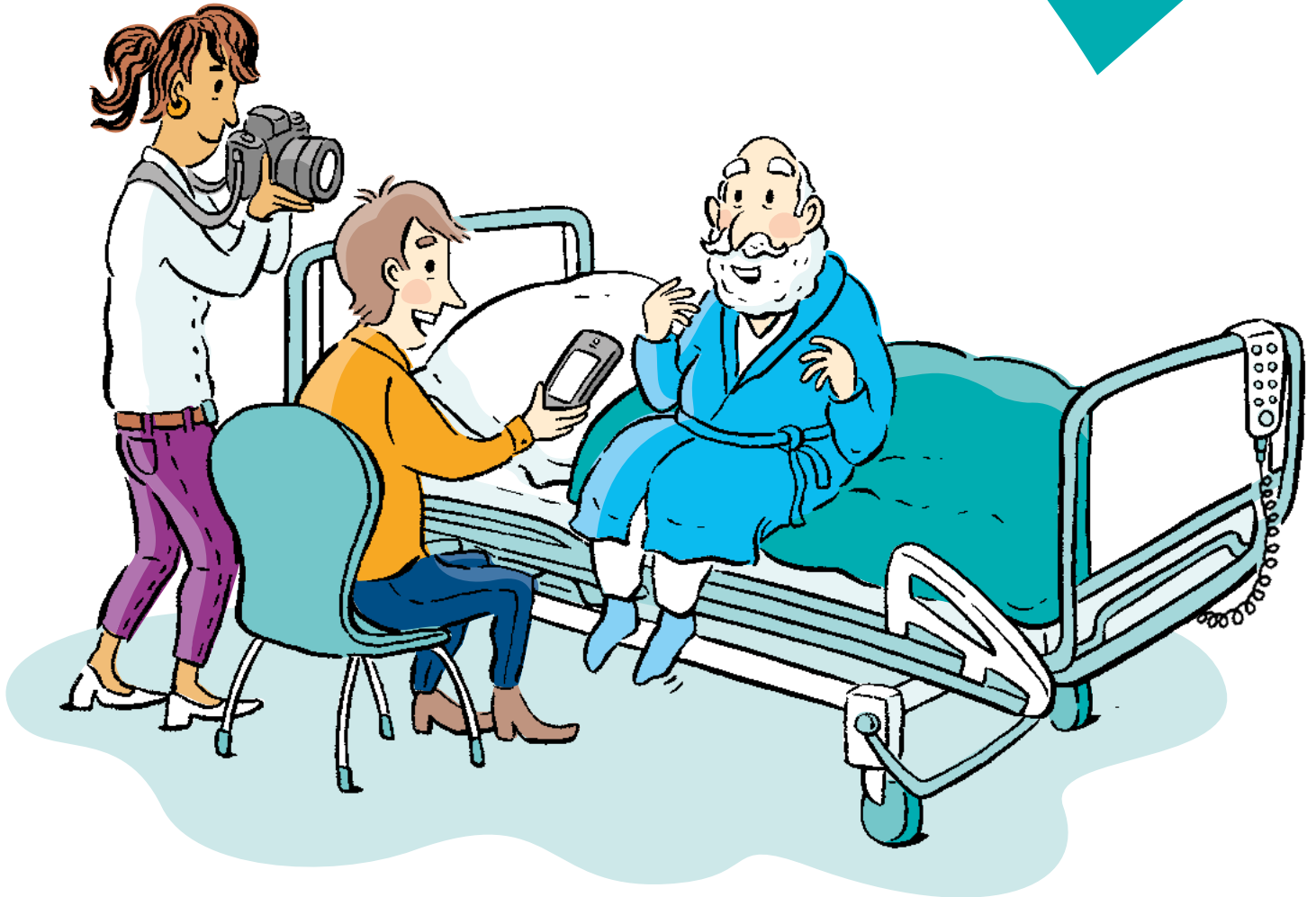
beforehand what you wish to share with the journalist. You may request a list of topics and questions beforehand. During an interview, you may also say that you do not wish to answer certain questions.

It is recommended that you state at the beginning of the interview that you would like to check the story before it is published. You have the right to check your own quotes in the story and have factual errors corrected.

Today, social media is an efficient channel for journalists to find real-life

stories. A public status update may catch the eye of news media and result in a request for an interview or comment. Be aware that a public status update on Twitter, Facebook or Instagram may spread rapidly and end up in the headlines, and the interaction may become uncontrollable. Extensively distributed personal content may be next to impossible to remove online if you change your mind.

Consider beforehand
what you wish
to share with the
journalist.



IN BRIEF

- During crises emotions may be stronger than common sense. Keep a cool head and consider what you publish.
- Be critical of the treatment-related advice you receive on social media.
- Always ask for permission to take photographs or record videos in treatment rooms.
- Be sure to respect the privacy of other patients and the staff as well as children and adolescents. Consider what you film.
- Be sure to protect your privacy.
- Deal with the media on your own terms.





At HUS Helsinki University Hospital more than half a million patients receive medical care annually. We have 25,000 professionals working for the best of all patients. We are responsible for providing specialized health care for the residents of our 24 member municipalities. In addition, the treatment of many rare and severe diseases is nationally centralized to HUS.

HUS is the biggest health care provider and the second largest employer in Finland. Our expertise is internationally recognized and accredited. As a university hospital, we continuously develop and evaluate our treatment methods and activities.

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