

## DO YOU FEEL INSPIRED TO INCREASE THE GENERAL AWARENESS ABOUT ALS? TELL YOUR STORY!

The Liga often receives the feedback that the illness does not get a lot of attention in the media and that people are not aware of it, and that is a shame.

This problem could be resolved by publishing more stories about ALS in newspapers, magazines and on television. These days more and more journalists contact our secretary requesting to interview an ALS patient and/or his/her family members or to make a documentary. That is the reason why ALS Liga is always looking for patients who are willing to be interviewed. In accordance to the Law on Privacy we always contact the patient first to ask for his/her permission.

We truly understand that it is not easy to tell your story in front of a camera, as it requires quite some energy and practical arrangements. However, if nobody does it, we waste opportunities to bring to light the disease and all of its challenges and increase the awareness amongst the broader public.

Of course you do not have to wait for a journalist to stop by! You can also take the first step yourself and contact them, for example the regional TV channel, the regional newspapers, radio stations, ...

We gathered some general do's and don'ts and information about interviews and how to prepare.

### 1. Goal of the interview

- The patient delivers a clear and accurate story
- The journalist delivers a clear and accurate story
- The target audience understands the story, gets the message and learns about the topic

#### 1.1 How to tell your story?

Be aware that there is a wide variety of "news" and information available: journalists are therefore looking for specific information. Think about your story and about what you want to say and when. If you like, you can contact ALS and discuss the subject and the approach with one of our staff members.

#### 1.2 How to ensure that the journalist reproduces your story as you like?

If you get the feeling that one of the questions is inappropriate or irrelevant, ask why that particular question is being asked.

If you do not understand a question, ask them to repeat and explain.

If there is a question that you prefer not to answer, do not avoid it, but let them know (and preferably tell them why you do not want to answer).

#### 1.3 How to captivate your target audience?

Describe the importance of the subject to the target audience: E.g to eliminate misunderstandings about ALS, to increase the awareness about the funding problems. Tell your story in a captivating way, being as objective as possible. Avoid self-pity and focus on the positive aspects and possibilities you still have.

Besides telling your personal story, mention some specific facts (and/or numbers) from the ALS Liga, E.g what is ALS about, the number of PALS, symptoms, treatments, ...

### 2 Get to know the media

There are national, regional and local media. Depending on your story and the audience you want to reach, you will get in touch with different kinds of media and will have to adapt your message accordingly.

A radio station requires a nice sounding voice and a good speaker, for television good images are important, and the written press will be interested in captivating stories and interesting discussion partners.

Then again, different newspapers have different interests. Some newspapers are focusing more on scientific and informative articles targeting a very large group of people (f.e. De Standaard), other newspapers focus more on regional and local news (f.e. Nieuwsblad, Het Laatste Nieuws) and will be more interested in specific activities organized by the organization or stories from local people.

### 3 How to reach the written press?

- Buy a selection of magazines and newspapers that might be of interest.
- Study the differences: is it published daily, weekly or monthly? Target audiences? Fixed headings (e.g Health, People, ...)
- Try to find the responsible journalist in the colophon and contact him/her (telephone, e-mail).
- Follow up on the contact. Usually more than one contact is required to ensure publishing.

## 4 Tips to survive an interview without a scratch

### 4.1 Select the medium carefully

Study the media that you want to focus on. Watch, listen and read the media, the programs, the newspapers you want to contact.

### 4.2 Prepare yourself

When the media interview a disabled person, they generally want to hear a very personal story. What kind of message do you want to convey? Where will you go into detail, what will you mention just briefly, and what information will you leave out? Think about what you want to say in advance.

### 4.3 A personal perspective can help, but do not forget the bigger picture

Do not try to make people feel sorry for you because of your disability, that is not relevant to the audience. You are more than your disability. Show your humanity by talking about your interests, your hobbies, your expertise in other domains. Other than that, you could also mention the patronizing health care system or the lack of funding.

### 4.4 Focus on facts

Facts are safer, clearer and can have a larger impact compared to an opinion.

In any case, make sure that your story is accurate.

### 4.5 Stay to the point

Even though you do not have to answer every question literally, avoid introducing a completely different subject without any clear link to the question.

### 4.6 Keep it short and simple

Media space is always limited: keep your message short and simple if you want it to be conveyed properly. The more you say, the more the journalist will have to cut. That increases the chances that only the information that you deemed less important will be kept, or you risk that information is put out of context and therefore changes meaning.

### 4.7 Use one-liners

Prepare one (or more) sentences that summarize your message or that can highlight some important things.

### 4.8 Avoid jargon

Assume that the audience does not know a lot about the illness. Many words that we use on a daily basis, are unknown to them, and therefore they will not understand them easily.

### 4.9 Repeat your message

Repeat what you want to say using different wordings, to make sure your message will be passed on.

### 4.10 Be silent if necessary

Do not say more than necessary. Leave out unnecessary details, only briefly mention any afterthoughts and stay to the point as much as possible. If you talk a lot, the chances are high that the journalist will select some irrelevant details that you have given and will therefore miss the main message while editing the text.

### 4.11 Avoid answering yes/no

The written press could use yes/no answers to put words in your mouth or to suggest answers that you are not entirely agreeing with.

### 4.12 Proofread the article

Make sure you can always proofread the article before it is published!

Discuss this in advance. While reviewing, only focus on mistakes regarding the content of the article.

## 5 Lastly:

- Patience is a virtue: the first contact and the actual publication might be a long time apart. And a first contact that does not seem to lead to anything at first sight, can sometimes be of interest later on.
- Make your work payoff: save the information you gathered (names, telephone numbers, publication deadlines, ...) on your computer. It will help you to gradually build an interesting database.
- In the media sector things change all the time, make sure you completely update your database at least once a year!

## Sources

[www.ethicom.be](http://www.ethicom.be) : tips about appearing in the press.

<http://www.handiwatch.be/?q=node/37> : tips for interviews.

'De persattaché is een boer' ("The press officer is a peasant") deals with setting up and maintaining press relationships. Author: **Koen Van den Broeck**, consultant at EthiCom (communication office).

'Bouwen aan persrelaties' ("Building press relationships") is a manual for spokespersons. This article (written by **Koen Van den Broeck**) was published in **Ad Rem**, 2002/6 – Magazine for Business Communication – publisher: Kluwer.

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