



NERVE TUMOURS UK

MEDIA GUIDELINES

The Media Standard supports responsible media organisations and professionals to show respect and care for individuals who live with Neurofibromatosis Type 1, Type 2 and Schwannomatosis.

The media should avoid words or descriptions which could further stigmatisation and stereotyping. It should always: Create a world where everyone is treated fairly whatever the person looks like.

Vocabulary

Use sensitive, non-stigmatising vocabulary. Name the condition and give an objective explanation of it. As Neurofibromatosis might take forms of physical and visible difference use a generic phrase, 'a person with a disfigurement' or 'facial difference' tend to be preferred.

Sensationalism

Refrain from over-dramatizing the condition or injury, and avoid parallels with non-human objects or characters from fiction or non-fiction who are defined adversely by their condition (i.e.: Elephant Man, Sandpaper Skin).

Personality

Avoid portraying the person as passive, helpless, a victim, to be pitied or inept. Avoid words or phrases that suggest the person's appearance indicates anything to do with their personality (i.e.: that they may be a villain). Avoid asking readers or viewers to express an opinion on someone's face or attribute qualities to a person based on their appearance.

Sympathy

Avoid evoking sympathy purely because someone has a facial difference or disfigurement; any sympathy should be warranted by the context — for example, if someone has been mistreated.

More on language

Nerve Tumours UK uses disfigurement as a collective term for the visual effect that a congenital, skin or eye condition, a paralysis, a scar or the treatment of cancer or another condition can have on the appearance of a person's face, hands or body. Nerve Tumours UK also respects the fact that some people dislike the term 'disfigurement' and so 'facial or physical difference' may be more widely accepted. In some instances, 'visible difference' may be used when relating to a disfigurement that affects a person's face and body.

Editing

It is common to see editing that involves dramatic music, black and white or grey filters and other dramatic devices. Unless the subject matter justifies this, i.e. hate crime or abuse, then the device creates sympathy without reason and further ostracises the person with a disfigurement. It's important to prioritise empathy over sympathy.

Interviewing

If conducting a live broadcast interview ask the individual to self-identify and provide you with their preferred term, i.e. 'I have a tumour and I prefer for it to be called a skin condition'. Speak to your interviewee first and have researchers/producers get to know them before the interview in order to figure out their preferred language, whilst ensuring everyone involved has read this Standard and understands the subject matter. Take the person's lead on how comfortable they are about their experience and how much they would like to share. If they would rather not share medical details or that of any form of a trauma as a result of the condition, then try not to probe for details. Consider whether it's relevant to the feature to discuss anything that may create drama or sympathy without reason.

Facts

When in doubt contact the charity on medical facts, statistics, etc. We are here to advise and can provide accurate and relevant information through our direct access to medics and other relevant specialists and institutions.

Nerve Tumours UK has produced this Standard to prevent poor media coverage given the success of standards from NGOs such as the Samaritans. Responsible media organisations should consult and accept the guidance of Nerve Tumours UK.

