



MEDIA GUIDE

Touretteshero presents BACKSTAGE IN BISCUIT LAND

GENERAL INFORMATION

- Touretteshero co-founder **Jessica Thom** (b. 1980) was diagnosed with Tourettes Syndrome in 2006. Tourettes Syndrome is a neurological condition, not a mental health disorder. An FAQ page about Tourettes can be found [here](#).
- When describing Jess as it relates to Tourettes, the proper wording is a “person with Tourettes” or simply as “having Tourettes.”
- Do not use the terms “afflicted with,” “stricken with,” “suffers from” or “victim of” because they carry the assumption that a person with a disability is suffering or has a reduced quality of life.**
- Although some aspects of the condition can be challenging, Jess is “brave” for all sorts of reasons, but not because she is disabled.
- Jess is among the 10% of people with Tourettes who have Coprolalia, the technical term for obscene tics. These tics make up a tiny proportion of what she says involuntarily. Jess considers these tics to be part of her condition and as such views any attempts to remove them as editing out her disability. However, Jess understands that under some circumstances this cannot be avoided.
- As a “wheelchair user,” all interview locations must be wheelchair accessible, preferably with an accessible toilet nearby. If relevant to the story, Jess should be described as a “wheelchair user” or as “someone who uses a wheelchair.”
- Do not use the terms “confined to a wheelchair” or “wheelchair bound” as they describe a person only in relationship to a piece of equipment and are also misleading with regards to Jess’ mobility.**

For radio and TV interviews, here are Jess’ preferences:

Most preferable: At the start of the piece, give a clear explanatory warning about the possibility of obscene language that puts it in the context of being an involuntary aspect of a neurological condition. There is an editorial precedent for this with broadcasters such as the BBC.

Acceptable: Remove potentially offensive language by dipping the audio.

Least acceptable: Beeping out potentially offensive language – this gives the impression that such language is deliberately intended to cause offense. This editorial decision should only be taken with direct consent from Jess.

For print and online interviews, here are Jess’ preferences:

When you are quoting Jess in an article, the tics may be removed. However, the tics may be included in quotes to help people understand Tourettes.

FYI: Because Jess’ tics are verbal, her writing/typing is 100% tic free.

ADDITIONAL INFORMATION

Jess' tics may intensify to the point where she completely loses control of her body and speech. These episodes, which she calls "ticcing fits" look seizure-like and require similar management. They generally last for only a few minutes but can last for several hours.

If this happens during an interview, the interview will need to stop until the fit has finished. If the interview is being recorded for television, the camera will need to be switched off. Jess does not consent to being filmed during these episodes under any circumstances.

Jess will be able to continue the interview as soon as the fit has finished. She will have a support worker with her at all times, and unless a specific request is made there will be no need to call an ambulance.

Jess is author of [*Welcome To Biscuit Land, A Year in the Life of Touretteshero*](#), which includes a foreword by Stephen Fry.

** For more information about the appropriate and accurate language when writing or talking about people living with disabilities, a great resource is the [Disability Language Style Guide](#) created by the National Center on Disability and Journalism at the Walter Cronkite School of Journalism and Mass Communication at Arizona State University.

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