



Guidelines for engaging with the media as a person with Tourette Syndrome

These guidelines are not meant to be extensive or mandatory but to provide some suggestions for people who have Tourette Syndrome (TS) who are considering being involved in some kind of media coverage. This is assumed to be TV or film but could be other kinds of media for example radio, magazine or newspaper articles. The guidelines cover a variety of themes picked out from interviews with people who have TS and their families who have had experience of being involved with the media. The general message from the people interviewed is that depending on the type of programme/media involvement and their experiences during and after filming or publication of magazine article, this can be an enjoyable and helpful activity to raise awareness of what it is like to live with TS. These guidelines are based on people with TS being approached by media or production companies who are asking for their involvement. The guidelines take the form of suggestions or questions to **ask yourself and perhaps the media/production company** before you become involved in the project.

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What to think about when preparing for a media appearance

- You should find out what type of programme you are being asked to be involved in.
E.g., a news item, documentary, an interview face-to-face, a reality TV or entertainment programme.
- It is important to check the credentials of the production company (have they had the approval of a Tourette Syndrome patient association for example), what kind of shows have they made before?
- In speaking with the media/production company ask about their 'approach' and motivation for dealing with this subject. Make sure that this is something you are comfortable with. By asking such questions, you can communicate how important it is you feel it is that your involvement results in a respectful portrayal.
- Ask questions about what the media/production company knows about TS. It's always a good sign if the producers have done their research, it shows they are open to understanding what potential challenges there might be for the person with TS during filming for example.
- Discuss what the media/production company's expectations and motivations are – are they 'looking for someone with certain (sensational, socially disruptive) tics' (e.g. coprolalia) or do they want to film someone with TS in certain situations. You may wish to ask for more details about whether they will ask to film you doing certain kinds of activities and do you have a choice in this?
- You may wish to find out if the media piece they want you to be a part of is going to be marketed as 'inspirational'. There is a recent trend by some in the disability community of pushing against the narrative of disabled people as needing pity, overcoming adversity (even when just living their everyday lives) and being painted as inspirational so you might want to decide how you feel about this (there is a great video about this issue Stella Young at TEDx Sydney 2014 https://www.youtube.com/watch?v=SxrS7-l_sMQ)
- Ask the media/production company what their reasons were for approaching you. You may wish to ask them how many other people with TS they have approached so far and if possible, ask for the reasons why others with TS decided against taking part?

- Ask lots of questions, ask to see written proposals so you can fully understand what you are signing up for e.g., what is the story about, who the audience is, where will the end product be shown.
- You may wish to ask where the filming will take place? Will it be in your personal spaces like home or work or in public spaces? Or will you be filmed while being followed around '24/7'?
- Ask how many hours of filming is estimated/what time commitment? If filming requires you to take time off work/take annual leave, you may wish to ask if you will be compensated financially?
- If you will not be paid for your involvement, you might feel comfortable asking if the media/production company would consider donating to a Tourette Syndrome patient association instead.
- You may or may not be offered a contract as part of your involvement. If this is the case you should read it carefully before committing and ask advice from friends, family, healthcare professionals and TS patient support associations. Make sure what your commitments are in the contract. You may wish to make suggestions such as adding a clause that allows you to leave the production if it turns out to be too stressful and/or if the agreements or arrangements are not met.

Tips, information, and advice section

Journalist/filmmaker's approach

- Often journalists or media companies reach out on social media and may ask you to be involved in a media project so when approached it can be a good idea to be cautious, apply these guidelines as suggested, and ask yourself the questions, what seems like a good idea can turn out as a negative experience.
- Accept that your goals may not be the same as the producers, and that it is OK to turn their offer down.
- Perhaps, as many people are doing these days, consider making a video/campaign yourself or with others such as a Tourette Syndrome patient association making something that is less sensational and more about awareness raising and understanding.
- Make it clear how and when you can be contacted. Some people may find it useful to reduce stress by being emailed rather than phoned or arranging a time when they will receive a phone call from media or production companies.

Filming/interviewing

As part of your information gathering and preparation, you should ask questions about the filming/recording/interviewing you are going to be involved in. Here are some examples of questions or issues you might wish to consider:

- Ask what steps or preparation, if any, will there be before the actual filming/recording?
- Ask if the media/production company/film crew have experience of working with neurodiverse people?
- Ask for a plan of what will happen before, during and after filming/interviewing to reduce stress of unscheduled calls and extra demands.
- Check for any potential issues that might arise during filming (try and think ahead and think how you might be affected by tiredness, co-occurring conditions etc.) and have a plan of what to do in those scenarios and have them agreed beforehand with the production company.
- You may wish to consider creating an information sheet about your specific needs in advance of performances/filming/interviewing to share with the production company.
- Accept that sometimes a media/production company may be working using a style where they do not have a 'set' idea of what will happen during filming– you will need to be comfortable with this or ask that it be more fully structured beforehand.
- Be cautious if someone from a media/production company is trying to convince you to get involved and talks about 'you feeling empowered by telling your own story', 'this is your chance' etc. This is your life, next week these producers, no matter how well intentioned, will have moved on to covering another subject with another group of people. You do not owe them anything, nor are you in any way responsible for educating general audiences.
- An important point to stress is that this is your lived experience and no one person is representative of all people with Tourette Syndrome, and be wary of questions you would be asked that would force you to speak on behalf of all people with Tourette's or make general, broad-brush statements, for example, "people with TS always..."

Your requirements

- Be aware that filming often involves long hours and physical exertion, depending on the type of programme it can often include having to repeat

'scenes' or filming things over and over until the director/media/production company get the results they wish.

- Ask for a schedule of filming – hours, location etc. With filming, there can be a lot of waiting around. Is there somewhere provided during filming for you to have snacks, drinks, relax (not only for the participants but also for the caregivers if there happen to be any present). Have a think about what things might help you during the filming.
- Tell the media/production company/crew what you are happy to do and what you are not comfortable with. Ensure they are aware of all of your requirements before filming.
- You may wish to have your requirements written down in an agreement/contract in writing beforehand.
- Ask if there will be any input/access to psychologists before, during and after production.
- During filming, do not feel afraid to ask for breaks or communicate if you are not happy with an aspect of the filming.
- The crew may be incredibly friendly but at the end of the day, it is their job to make this film/do this interview/radio show and they are being paid so there is an additional motive for them. Film of TV crew are on a budget, they have deadlines, they have a vision and you must know and be realistic about whether that vision matches yours.. Especially if you are not being paid, do not feel like you need to do things you are not comfortable with or do what they expect you to do for their project just to please them or to be polite.
- Make sure that you only film and talk about what you are happy to talk about.
- You may also want to ask about or discuss with the team the issue of including something in the programme where you can describe or explain how the public can better respond to people with TS condition. Therefore not just showing what it is like having TS but how small changes in people's behaviour can make such a big difference to reducing stigma.
- If you feel comfortable, you could ask that at the end of the programme there is some signposting information to the Tourette Syndrome patient association for people to find out more information. Also potentially some signposting to mental health charities depending on the content of the programme.

Editorial control

- Before committing to the project, you can ask about editorial content. You can ask if you can see the edit before the transmission date and before the story goes to air or before the article is printed and get this in writing beforehand if it is something, you need from the project. You can ask what

the title is going to be. Sometimes the titles of TV programmes focus on a sensational aspect of TS or one aspect such as swearing - you may not be comfortable with this, and it may be helpful to know in advance.

- Ask about and be aware that it may be a long time before the programme you were involved in will be released and shown or the story printed.
- Ask yourself if you are happy for whatever the result of the programme/media involvement that it will be around 'forever', made available online, and may be repeated in the future without you being informed.

Release & post-release

Public reaction

- In regard to public feedback to your media appearance be aware that not everyone is going to like you or believe you and you cannot please everyone.
- Be aware that the involvement is literally "15 minutes of fame" – nothing will change, you still have to do the dishes and go to work.....possibly just with more public scrutiny.
- Ask yourself if you and your family handle/ignore or continue to live or bounce back from any negativity following on from a media experience.
- Ask yourself if you and your family are comfortable that you may continue to be recognised from your involvement in the media not just shortly afterwards but for the longer term.
- If your media involvement is a television show or film, there may be further media coverage in newspapers; for some publications 'clickbait' titles are common. Your experience and story may be summarised into a blunt or crude one-liner.
- Make sure social media privacy settings are secure and that all of your images on your personal profiles are not set to public. Otherwise, this means individuals/newspapers/media outlets can access them without your permission for articles on your media involvement.

Questions to ask yourself section

Your motivation

- Ask yourself why you are considering getting involved.
- An important thing to consider is whether the media appearance is something that would be good for you the person with TS. You may also wish to think about any effects of you being on TV, for friends, family or colleagues etc. might they be upset or unsupportive of your involvement.

- You may also want to discuss this issue with your healthcare professional, GP, therapist and of course ask the advice of a Tourette Syndrome patient association. They may be able to put you in touch with others with TS who have been involved in the media.
- In your own mind, know what you want your message to be and make sure that the media/production company is fully on board with this view. If they are not, then this may not be the project for you. Adhere to your own values and make sure you feel comfortable with whatever is planned from the outset.
- An important piece of advice is do not share things you do not want to share.
- Be clear what you want to show the public. Is it the daily realities and struggles of TS, as not many people know what it is like to live with it, or how you learnt to live with TS despite the extra challenges you had to meet because of it?
- Do not allow the media/production team or anyone to pressure you into doing activities or depicting TS in a certain way during filming/interviewing. If you are feeling pressurized, then it might be time to take a break, step back and make someone aware you are feeling uncomfortable.
- Manage your expectations of being involved: don't try to speak for everyone with Tourette's, just speak for yourself and don't feel you can or need to change the world by being involved in this programme
- Ask yourself whether this is the 'right time' in your life for you to be involved – perhaps you already have stress from other life events happening?

Thinking about your family and friends

- It is important from the start to ask questions to help you make your decision as to whether you and your family want to be involved in whatever media project you are being approached about.
- Depending on the context and type of media involvement, being involved in a TV programme can be incredibly intrusive in your and your family's lives. You may wish to give a good deal of thought as to whether you feel comfortable showing (parts of) your private lives on TV.
- Some films/TV companies may want to see your personal life in action, so you will need to check if your friends and family are comfortable with this. This is especially important if you would be involving other people with TS, children, or otherwise vulnerable people; anyone who may not be able to fully understand the consequences of appearing in the media or who may be likely to face negative or mocking public opinions.
- Consider whether you are prepared and have the resilience to cope with media and public interest. Could there potentially be criticism, mockery or

abuse after the broadcasting of the TV programme? Ask yourself if you (and your family) can deal with harsh judgement, especially on social media and how you would engage with it, if at all.

- Do you have a strong support network of family and friends that can be there for you, perhaps to help you deal with any negative outcomes?
- Do you have access to psychological support, either from your own healthcare professional or provided by the media/production company?
- Ask the media/production company about aftercare/support should it become difficult to cope with.

Enjoyment

The reason for these guidelines has come from many years of listening to people with Tourette Syndrome and their media experiences. If you do decide to be involved in a TV programme or similar, it can be a positive and life-affirming experience. It can be fun and exciting and can be an opportunity to show how wonderful people with TS are.

The guidelines aim to empower someone to ask some questions of the production team, writers and/or directors on how they view TS. Also, tell them why you are doing this, for example, to help the public better understand and be empathic towards people with TS. By discussing this and asking for assurances that this is not just some funny stunt or angled for entertainment (unless you are OK with that, of course!) This will hopefully lead to a more satisfactory and enjoyable result for you. If you feel unsure, after reading these guidelines, and speaking with friends and family, whether you want to commit to the media involvement, then perhaps consider withdrawing or saying no, there will always be other opportunities in the future.

We would love to hear your feedback on these guidelines!

Seonaid Anderson PhD is a chartered research psychologist & freelance neurodiversity consultant