

Guidance for Branches and Groups for activity around the death of a high profile person with MND, supporter or MND Association patron

The MND Association has prepared responses to use when the death of a high profile supporter, patron or person with MND is announced. This allows us to respond sensitively and in a timely manner even if the announcement comes out of hours.

We realise you may wish to respond through your social media channels in certain circumstances, although there is no requirement for you to do so. If you feel you would like to react publicly, we hope the following guidelines are useful.

- It is really important NOT to share information until it has been publicly confirmed. You may hear that a certain person has died because they know someone who you know. But we should NOT be announcing anyone's death – that is for their family or their professional channels to do. We can then 'react' to it.
- Your message should reflect the fact that you have 'heard' and not that you are 'announcing'. For example: *We're so sad to hear XXXXX has died*
- Follow the lead of the MND Association – we have processes in place and take account of the person's relationship with us, the wishes of their loved ones and their position in the community. We will use our website, social media channels and the media to share announcements and messages. So the 'safe and easy' option is to retweet, share and like our posts. You'll find us @mndassoc on Twitter and Instagram and @MNDAssociation on Facebook.
- Don't use a person's social media handle in your message about their death, write their name out in full accompanied by any titles, for example Dr or OBE. This is because some usernames may not be appropriate to use in a message.
- Hashtags - # - you may wish to follow the Association's example around the use of hashtags when a person dies – we don't use them. However, hashtags are often adopted quickly by general consensus. If you do use a hashtag, please sense check its suitability.
- Follow the MND Association's lead around 'asks'. Whenever possible we work with people, families, clubs and companies to ensure that any asks align to the wishes of the person and / or their family. It isn't appropriate to, for instance, tweet a message of condolence and include a link to the donate page on our website. It is up to the family or official channel to share any wishes they have around donate asks. As an Association we would then share that message should we be asked to by our followers. Please do the same on your channels.
- It is perfectly ok, indeed a personal touch, to include a reference to a specific interaction / relationship you had with the person in any message you post. For instance, the person may have supported a fundraising event or attended your

meetings. You may wish to say: *We are grateful for all the support XXXX gave to us as a branch – they always brought the tastiest cakes to meetings / gave their time to support our annual summer fete etc.*

- You may wish to accompany the message with a photo of them at your event (as long as you had permission from all featured in the photo to use it).
- Please remain respectful and consider confidentiality. It is not appropriate to share personal details or medical information. And do not share details about their family which haven't already been shared officially – particularly the names and ages of family members under the age of 18.
- As an Association, we avoid euphemisms around death (lost, passed away etc), preferring to say 'death', 'dying' and 'died'. We appreciate not everyone is as comfortable with that but would ask you to consider following our lead.
- If you are in any doubt about what to do, it's usually safer to do nothing in this instance and seek advice.
- If you receive any enquiries from the media following the death of a high profile person who has been involved with your branch or group, please refer them directly to the Communications team (contact details below).

If you have any questions around this either now or at the relevant time please don't hesitate to contact us.

Email: communications@mndassociation.org

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