

# Families WhatsApp Network Guidelines & Expectations

## Purpose

The SMA Families WhatsApp Network is a platform for SMA family members aged 18+ from across the UK to connect, support, and help each other. The group can serve as a place for families to:

- Share experiences and information related to SMA
- Provide emotional support
- Build a sense of community
- Connect families with resources
- Provide information about SMA-related issues

## How old do I have to be to join?

You must be aged 18+ to join this network

## What is an SMA family member?

The definition of family can vary from culture to culture and from individual to individual. For SMA UK, we know that all families are different and when we talk about family, we are referring to a group of people who share a strong emotional bond and support each other through their journey. This typically includes parents, siblings, grandparents, uncles, aunts, cousins, in-laws, stepparents, and other extended family members who are not directly related by blood or marriage but are considered part of the family unit. You could consider your best friend to be your brother or sister, it is not for us to dictate who can and can't be part of your family.

## Communication

Use the group as a means of communication and to stay connected, but be mindful of the frequency of messages. It's okay to take a break from the group if it becomes overwhelming.

## Moderators

The group is to have two moderators who are from the SMA community, to provide support, advice and assistance through WhatsApp chats

## Outreach Team

The SMA UK Outreach team are also part of this network and are members of the network, to assist the moderators, and to help with any information shared or questions asked.

## Privacy Settings

Please review your WhatsApp privacy settings. Go to WhatsApp's settings and select '**Account**' and then '**Privacy.**' Make sure the settings for '**Last Seen,**' '**Profile Photo,**' and '**About**' are set to your preference. You can also choose to block certain contacts from seeing your information. Once you have joined the WhatsApp network, others in the network will be able to see your mobile number.

## Tone

Please try and keep the tone of messages friendly and positive

## Feedback

We encourage all members to share their thoughts and feedback on the group, and be open to suggestions for improvement.

## Respect

All members should respect each other's privacy and personal space. Refrain from posting or sharing sensitive or personal information about others without their consent.

## Removal from the network

If anyone is observed breaking the [Network and Volunteering Guidelines](#) they may be asked to leave the group