

## IT'S TIME TO TELL YOUR STORY...

IF YOU LIVE IN NORTHERN IRELAND AND SUFFER FROM A RARE OR HARD TO DIAGNOSE CONDITION OR ARE A FAMILY MEMBER OR CARER OF SOMEONE WHO DOES, WE WOULD LOVE FOR YOU TO GET IN TOUCH AND SHARE YOUR STORY.

## HELP TO RAISE AWARENESS

EDUCATE US, HELP BRING PATIENTS WITH SIMILAR CONDITIONS OR SYMPTOMS TOGETHER AND DECREASE RARE DISEASE LONELINESS.

HAVE A GO YOURSELF OR IF YOU FEEL UNABLE TO WRITE YOUR STORY BUT STILL WISH TO CONTRIBUTE, MAKE CONTACT WITH US AND WE CAN CO-WRITE A STORY WITH YOU OR GUIDE YOU THROUGH THE PROCESS.

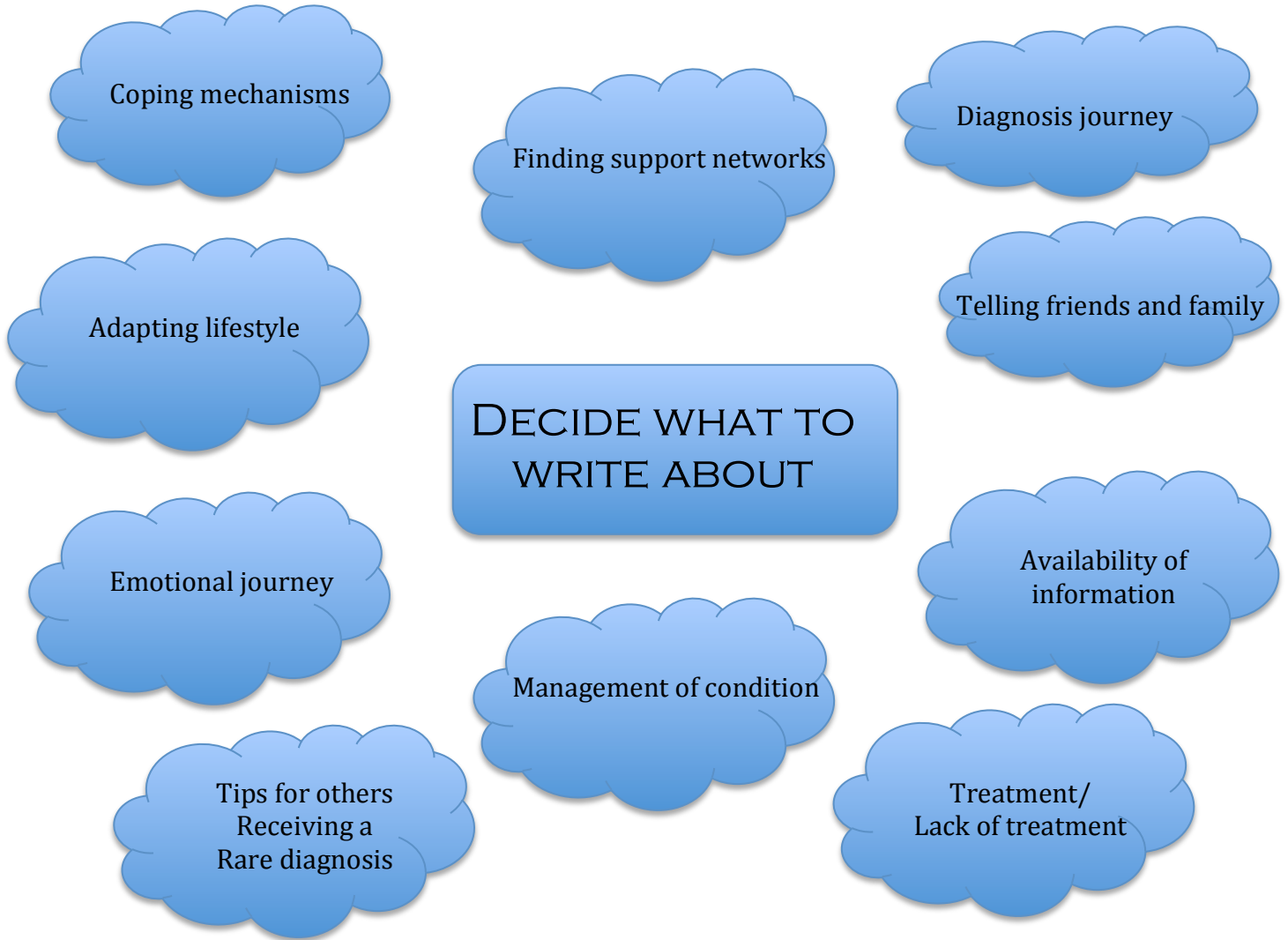
[WWW.VOICES@NIRDP.ORG.UK](mailto:WWW.VOICES@NIRDP.ORG.UK)

- PLEASE INCLUDE YOUR NAME AND A FEW LINES ABOUT WHO YOU ARE AND WHAT YOU ENJOY.
- IF YOU ARE WRITING A STORY ABOUT YOUR CHILD AND THEIR CONDITION, PLEASE STATE THEIR AGE AS SOCIAL MEDIA RESTRICTIONS MAY APPLY.

## SHARE YOUR RARE!!



**HAVE A GO:**



- DO:
- USE EVERY DAY LANGUAGE AND SPEAK FROM THE HEART, IT IS MORE RELATABLE
  - FOCUS ON AN ASPECT OF YOUR CONDITION
  - TRY TO SHARE THE DIFFICULT PARTS
  - INCLUDE A FEW PHOTOGRAPHS
  - KEEP IT SHORT – 500 - 1 000 WORDS

- Do Not:
- WRITE ABOUT EVERYTHING YOU HAVE BEEN THROUGH
  - SHARE INFORMATION THAT MAKES YOU UNCOMFORTABLE OR YOU FEEL INVADES YOUR PRIVACY
  - SHARE POLITICAL ISSUES
  - WRITE OPINION PIECES
  - ADVERTISE OR PROMOTE COMMERCIAL COMPANIES
  - PROMOTE FUNDRAISING FOR AN ORGANISATION

WE MAY EDIT YOUR STORY BUT WILL SEEK YOUR APPROVAL BEFORE PUBLISHING IT.

IF YOU ARE NOT READY TO SHARE YOUR STORY BUT WANT TO RAISE AWARENESS OF YOUR CONDITION OR FOR RARE DISEASES IN GENERAL, PLEASE SEND US A PICTURE OF YOURSELF ALONG WITH YOUR NAME, YOUR DIAGNOSIS (OPTIONAL) AND A SHORT COMMENT TO ACCOMPANY THIS INFORMATION. THESE WILL BE PUBLISHED ON OUR WEBSITE AND ON SOCIAL MEDIA.



“I find it hard to connect with people in the same position as myself and can feel very isolated. I would like to find activities that would suit my condition and meet new people.”

Judy Smith

Addison’s Disease