

USER GUIDE

camRARE

FOR COMPLETING YOUR 'THIS IS ME' RARE PATIENT PASSPORT



A FILLABLE PDF WITH SPECIAL FEATURES

The passport can be opened and filled out using most PDF apps on a computer, tablet or phone. We've trialled many options and recommend downloading the free version of Adobe Acrobat [here](#) for the best user experience. Inserting a photo and using the hover guide function works best in Adobe.



USING THE GUIDE NOTES TO FILL OUT YOUR PASSPORT

To access the guide notes in Adobe Acrobat PDF reader, use the 'hover' feature, holding your cursor over a box for a moment to reveal suggestions for each section. Feel free to use this guide, or personalise the passport to your needs.

CLINICAL INFORMATION

Medications and dosage



List medications - dose in mcg/mg/g, frequency and form and/or link to a medical alert website

In other PDF readers, the hover may not work. The same guide notes can be found in the CamRARE Patient Passport Reference Guide document attached in your passport email.



OTHER TIPS ON FILLING OUT YOUR PASSPORT

It's tempting to jump straight into filling out your passport, but we'd recommend reading the guide notes and then making some notes for each section. If you're filling this passport out on behalf of someone you care for, or you're a professional helping to complete it, take time to talk through what's important to the owner and how they'd like things phrased. You can edit it as many times as you like, especially when things change.



Information to gather together before you get started:

- NHS or medical ID number
- Your medications
- Dates and outcomes of emergency care visits
- Your GP surgery details
- Medical specialist details
- A good summary of your diagnosis. If you have one, a trusted info weblink
- Contact phone numbers and emails
- Your height and weight in metric measurements
- A current 'headshot' - a photo of your face that's a good likeness of you



ADDING A PHOTO

In Adobe Acrobat, adding a photo is simple. Just click the photo box, and a pop-up box will ask you to select a jpeg/png file from your device. A camera or phone photo is fine. Head and shoulders facing front in good light works best. And feel free to smile!

Without a PDF app, you can still add a photo, but you may need to crop it a little to fit the space.



PRINTING & STORAGE

Before printing your passport, ask someone else to check it. If they didn't know you, would they have the right information? Do they get a good sense of you and your care needs? Is there anything they think is important to know about you, as a family member, caregiver or friend, that you haven't mentioned?



During the passport trial, people liked having multiple copies of their passport and used it differently. Some carried it on a lanyard in their wallet/bag; others kept A4 size in a summary medical folder. Some people created a PDF or image file and keep it on their phone.



Print at 100% size (A4), double-sided and in colour for best results.



The passport can be stored flat. You could keep it in a plastic wallet and store it in a ring binder folder or punch holes on the left side and clip it into a ring binder.



Trimming & folding to store in a plastic wallet on a lanyard is also an option. Trim along the dashed scissor line and follow the folding guide on the passport, or watch the short film on [YouTube](#) to see how it folds if you prefer a visual guide.



No printer? Online companies provide printing services, e.g. Helloprint and Vistaprint.



In the future, we hope to sell branded lanyards and plastic wallets, but to get ahead, try [here](#) for reasonably priced lanyards with safety catches and [here](#) for plastic wallets. *We do not work with these outlets and cannot vouch for their services, so we shop around.



SHARING

In trials, people shared their passports with routine and emergency health care professionals, teachers, social workers, in extracurricular situations like clubs and with family and friends. Feel free to use yours wherever it will help you communicate you, your condition and your needs.

ANY QUESTIONS?

If you have any problems completing your passport or printing, email: lindsey@camraredisease.org