

What I Need You to Know

A Health and Care Record
for Me, My Family and Carers



Royal College of
General Practitioners



Supported by
Public Health
Agency



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A Health and Care Record
for Me, My Family and Carers

Guidance Notes



Royal College of
General Practitioners



What I Need You to Know (My Healthcare Passport[®]) is designed for anyone who is living with a long term complex medical condition. It aims to keep in one place the key information about the health and care requirements of the person who owns it, and to be updated as their health and individual circumstances change.

All of the information in the Passport belongs to the owner. It is completed and updated by the owner or whomever (among family or carers) looks after it on their behalf, with the help and guidance of healthcare staff.

As the Passport's owner you can use it to help you understand your medical condition as it changes, to provide key information to all those among family and carers who are supporting you, and to coordinate the information which is given to you by different health and care professionals.

If you are reading this as a doctor, nurse, pharmacist, allied health professional or other health and care staff member and are supporting a Passport owner or their carer, you are asked to help them to keep the content of the Passport accurate, focused and brief. This may sometimes include writing information which is important to the patient or their carers into a relevant section (with their agreement), or providing printed information which can be stored in the pockets provided.

From a healthcare perspective, the Passport allows key and evolving information to be clearly communicated to a patient and their carers. It can also act as a focus for review and discussion.

It is not a clinical record and should not be used alone to make a clinical assessment. Complete clinical records remain within the healthcare system and should always be accessed when detailed up to date clinical information is needed. Rather, it is a record of the patient's (and/or their carers') knowledge and understanding about their medical condition(s), the unique challenges which they face and the unique resources which they bring to help them to manage these.

Completing 'What I Need You to Know'

Information which also particularly involves health and care staff is highlighted throughout.

When you are writing in My Healthcare Passport®, it is very important that writing is brief, focused and legible, so that others will be able to read it quickly and easily.

All those updating My Healthcare Passport® should sign and date each entry.

The content of your Passport should be reviewed and updated at least every six months, or when there is any important and lasting change to your health.

The front sheet contains information about the Passport owner (name, address, contact numbers, next of kin). Please complete this.

Your health and care number can be accessed via your GP and also written in here.

Section 1. All About Me

This is designed to be completed by you and/or by those who know you best.

You may however wish to seek the support of a member of your healthcare team to help you complete some aspects of this. Please only write important information, as briefly as possible.

You may have communication needs. These might be very detailed - communication guidance written by a Speech Therapist, to go into the pocket - or they may be very simple, such as "Please allow me time to answer and speak slowly." or "Please stand on my right side when speaking with me." You may simply wish to write down any difficulties you have with hearing or vision.

The other information which goes in here depends on you as an individual. For example:

- If you have any preferences or restrictions around food or diet, these should be added here.
- If there are important things about your daily or weekly routine, please describe these briefly.
- If there is important information about sleep or about interests or habits, please include these briefly.
- Information about spiritual beliefs and religious practice might also be included here.

- You may wish to add information about your work, whether in the past or present, or around valued hobbies.
- You may wish to add information about your behaviour, things which you find difficult or upsetting, or things which help you to relax.

This is information for anyone who may be involved in your care in future. If you are tired or unable to communicate for any reason, this contains information about you which it is important for them to know.

Section 2. I Can Complete Many Tasks with Proper Support.

This is what I need help with:

In this section, please add practical information about any things which you need help and support with on a daily basis. It is designed to explain your individual requirements to anyone involved in providing you with care and support.

You may want a member of your health and care team, such as an Occupational Therapist, or an experienced care worker, to help you with this.

It aims to prevent you, or your carers, from having to repeat this information every time you meet with new health and care staff.

It might also be used as a basis to discuss your individual requirements with any member of your healthcare team, who will help you to adapt or modify what is written here. It might also be used to help you to find ways to manage new challenges, or to set goals or aims.

The content of this section should be reviewed and updated regularly as it may change.

Please include brief information here about:

- Any practical support you may need to help you minimise risks due to problems with vision, hearing or unsteadiness.
- Advice about support or equipment which you need for walking or getting around.
- Help or support which you need with any aspect of personal care, including feeding.
- Equipment which you find helpful and serial numbers.
- Help or support which you need to complete difficult or complex tasks.
- Advice about ways in which you can minimise pain or discomfort.

Section 3: My Health

Please ask your GP practice to provide you with a printed record of your medical history. If your health changes, you will require a new updated printout to reflect the changes. Please fold and keep in the pocket provided.

Section 4: My Medication

There are 2 pockets here. One is for allergies. If there is anything, including any medicines, which you are allergic to or have reacted badly to, your GP will provide a printout of these, which can be kept in the polypocket provided.

The second polypocket is for a list of your regular medicines. You can access this from a number of sources. Alongside your repeat prescription is a reorder list, which you might want to store here.

Alternatively, your pharmacist might provide you with a list of what your medicines are and what they do, which can be stored here. This also needs to be updated and replaced when things change. An example would be if you were to go into hospital. If your medicines are changed, you can ask the hospital staff for a list of your new medicines and what each is for.

There is space here to record "Advice About My Medication". This is a space to record specific information about any new medicines and how and when these need to be taken. There are some medicines, (such as those for Parkinson's), which need to be taken at very specific times. Other medicines (such as some taken for osteoporosis) need to be taken in a particular way.

Please ask your Pharmacist or your GP or specialist if there is any special information which you and your carers need to know which can be included here.

Section 5: My Healthcare Team

Ask each member of your healthcare team to complete this, with their role and contact details. There is a space provided to store cards given by health and care staff.

Section 6: What My Healthcare Team Wants You to Know

This section is completed by your healthcare team if/when there is important information which they want you and/or those caring for you to know.

This might take the form of written advice, about avoiding falls, preparing food, right diet or a plan of exercise or activity. It might also be pre-printed information, such as a self-management plan or an information prescription.

Section 7: Information and Advice About Issues Which May Need Urgent Attention

This section is just for those people who have very specific and predictable risks associated with their condition. It is a space for healthcare specialists to add important information about any 'red flags', and issues which might arise which might need you to act quickly.

This might take the form of written information (e.g. when to contact the hospital directly) or of pre-printed information provided by your healthcare specialist team (an example would be 'recognising and treating hypoglycaemia'). This will explain any signs to watch out for and what action you should take if they develop in order to minimise your risks.

Many people will not require any information in this section.

Section 8: My Medical Condition

This is a place to store printed information about your medical condition, which might be of interest to you, your family and carers. If your condition is rare or unusual, it is also very useful to have this information available for health and care staff.

Section 9: My Family, Friends and Carers

This is a place to record and store important contact details. This is of use to you and to those who are supporting you.

Section 10: Useful Resources for Me and My Carers

This is a place to write and store any information about useful websites, support groups, books, events.. anything of interest or help.

Section 11: In the Event of...

Looking ahead, everyone faces the possibility that their health will deteriorate at some time, and that they may not be well enough to communicate any strongly held wishes or preferences to others.

Some people feel safer if they know that they have recorded their wishes (in particular, if there is anything which they wish to avoid) and can keep them in a place where they can easily be accessed if anything should happen.

This section of the Passport provides a place to store any documented, strongly held preferences.

It is very important to talk these through with someone from healthcare staff, such as your GP, if they include preferences about healthcare. If not, you may wish only to share them with those closest to you, or to keep them private for the present.

If you do have strong preferences regarding healthcare, your GP can try to ensure that these will be read and taken into account by anyone who is making decisions about your care in the future. If you have discussed them with your healthcare team, they will try to ensure that others, such as the ambulance service, know and understand that you have taken time to write out your preferences. All decisions will always be made on the basis of your best interests, but your views or preferences can help to guide this.

If your family, carers and/or GP know that you have strong preferences and that these are stored in your Passport, they will do their best to ensure that they are accessed at the right time.

You may also wish to store information for family, friends or carers here, to be accessed in future.

You have legal rights which you might want to learn about, such as Enduring Power of Attorney (if you wish to nominate someone to look after your finances in future), or an Advance Directive (if you wish to undertake a legally binding refusal of treatment in future). Your healthcare staff or a legal advisor can explain these options to you. The Passport provides a place to store any documentation in this regard.

The information within your Passport belongs to you and to anyone whom you choose to share it with. If you give this to a member of your healthcare team (for example, if you go into hospital), please ask them to respect its confidentiality and to share the information within it only with those who are involved in your care and need to know.

When updating the Passport, please include only KEY information (about continuing changes). Please keep all entries brief, focussed and legible. Please sign and date each entry.

Royal College of General Practitioners Northern Ireland
4 Cromac Place, BT7 2JB Tel: 020 3188 7722

My Healthcare Passport[®] is a unique individual health and care record, designed for anyone who is living with a medical condition which requires on going care and support and for their families and carers.

My Healthcare Passport[®]

Living with a medical condition may involve meeting many new people. Keeping family, carers and health and care staff updated about changing requirements can be difficult, repetitious and tiring. This passport aims to act as a core record of how my individual health is evolving and of information required to support my health and wellbeing.

It is designed to be completed, updated and kept primarily by me, the passport's owner, or any member of my family or carers on my behalf. Health and care staff may also add to, or with my permission, change and update the key information contained in this record. For example, my GP may add a suggested management plan, Speech Therapy might add information about communication. Any member of my health and care team, with my permission, may wish to add key information.

The passport aims to provide information about my healthcare requirements which can be accessed, with my permission, by anyone involved in my support or healthcare. For example, it may be useful to take into hospital, or it may be used to update my family and carers, when a situation is changing.

My GP and other members of my health and care team hold accurate and up to date clinical records regarding me and my health but these cannot always be accessed easily by those non-medical staff visiting me in my home or by those whom I meet in other settings. This passport may help in those situations.

If, for any reason I am unable to communicate for myself, for example due to illness, the health and care passport explains the day to day requirements for my care, and will be updated by me, my family/carers or my health and care team, if these change. It may also contain important information about my preferences and wishes regarding healthcare, if my health were to deteriorate for any reason.



This Healthcare Passport belongs to:

Name: _____

Address: _____

Contact Telephone Number (s): _____

Health and Care Number (my GP practice can provide this):

Next of Kin: _____

Name: _____

Address: _____

Contact Telephone Number(s): _____



All About Me

If, for any reason, I am unable to communicate for myself, this is the information about me **as an individual** which my family, friends and carers would want you to know. It may contain anything of key importance about **me as an individual**, expressed as briefly, clearly and legibly as possible.

For example:

- My core values/spiritual beliefs, as they relate to my care
- My daily/weekly routine
- How I express pain/anxiety
- My sleep

What I would like you to know
about **me as an individual**,
continued:

- My food preferences and diet
- My likes, dislikes and interests
- How to communicate with me
(if I have communication
difficulties)
- Work interests
- How I like to relax
- Any other key information of
importance.

(If needed, a communication sheet
explaining specific communication
requirements may be prepared
with help from a Speech and
Language therapist and stored in
the plastic envelope).

All About Me

Date: _____

Recorded by: _____

Detail:

All About Me

Date: _____

Recorded by: _____

Detail:

All About Me

Date: _____

Recorded by: _____

Detail:

All About Me

Date: _____

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All About Me

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Detail:

All About Me

Date: _____

Recorded by: _____

Detail:

I Can Complete Many Tasks with Proper Support.

This is what I need help with:

(An evolving record of my care requirements).

This will be updated by me, my family or carers. My healthcare team may also comment on, modify or update this information.

It will need to be reviewed regularly and updated as needed. Examples of the type of Information to be included:

- Hearing difficulties
- Visual problems
- Pain and discomfort issues
- Mobility/support needs
- Risk of falls
- Personal care (washing/dressing)
- Eating and drinking
- Toileting
- Equipment which is helpful to me
- Other.

Date: _____

Recorded by: _____

Goals and Limitations:

Date: _____

Recorded by: _____

Goals and Limitations:

Date: _____

Recorded by: _____

Goals and Limitations:

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Date: _____

Recorded by: _____

Goals and Limitations:

My Health

My Medical History

This contains a medical summary of current and previous problems, as printed by my GP. It will be updated by my GP only if a new and significant problem develops.

Important Note: My medical and nursing teams do not rely on this information as they have their own clinical record. This is simply a record for me, my family, carers and any health or social care professional who visits me at home without access to my records. There may be some delays in keeping this updated and my GP can be contacted if there is any doubt.

My Medication

This contains:

- A record of my current repeat medication, provided by my GP or pharmacist
- A list of allergies, as provided by my GP. If I develop any new allergy, my carers or I will ask my GP to update this. This is for my information, and that of my family and care team.
- Any special instructions regarding my medications
- Where to find my medication
- The computer record in my GP surgery will contain the most updated information.



My Healthcare Team

- Who to call
- When to call
- How to call.

I, my family, my carers and healthcare team will add contact information about my healthcare team here, for example, my GP, the Out of Hours Service for my area, Specialist Nurses, Social Worker, Care Manager, Occupational Therapist, Physiotherapist, Speech Therapist, Hospital Consultant.

Note to Health and Social Care Teams: Please sign and date this record legibly with your contact details, and advise on how and when you can be contacted by this patient and their family/ carers.

My Healthcare Team

Name: _____

Job Title: _____

Address: _____

Telephone Number: _____

Role: _____

When to contact me: _____

Name: _____

Job Title: _____

Address: _____

Telephone Number: _____

Role: _____

When to contact me: _____

My Healthcare Team

Name: _____

Job Title: _____

Address: _____

Telephone Number: _____

Role: _____

When to contact me: _____

Name: _____

Job Title: _____

Address: _____

Telephone Number: _____

Role: _____

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My Healthcare Team

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Job Title: _____

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My Healthcare Team

Name: _____

Job Title: _____

Address: _____

Telephone Number: _____

Role: _____

When to contact me: _____

Name: _____

Job Title: _____

Address: _____

Telephone Number: _____

Role: _____

When to contact me: _____

Cards from healthcare
professionals



What My Healthcare Team Wants You to Know

Any additional or evolving information and advice from my healthcare team about my medical condition, for those involved in my practical care, about issues which are current and issues which are anticipated.

This may be updated by my healthcare team over time.

For Health or Social Care Teams:

Please record any new key information about current or anticipated issues for me, my family and carers in this section.

Please write legibly and sign and date each entry. Management plans can be stored in the polypocket.

Date: _____

Recorded by: _____

Key Information and Advice:

Date: _____

Recorded by: _____

Key Information and Advice:

Date: _____

Recorded by: _____

Key Information and Advice:

Date: _____

Recorded by: _____

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Date: _____

Recorded by: _____

Key Information and Advice:

Date: _____

Recorded by: _____

Key Information and Advice:

Information and Advice About Issues Which May Need Urgent Attention

If there is a risk of any issue arising which would require urgent action, please record a brief advice plan here.

Please write legibly and sign and date each entry.

Enclose urgent pre-printed management plans in the pocket provided.



Date: _____

Recorded by: _____

Key Advice/Information about Issues of Potential
Urgency:

Date: _____

Recorded by: _____

Key Advice/Information about Issues of Potential
Urgency:

Date: _____

Recorded by: _____

Key Advice/Information about Issues of Potential
Urgency:

Date: _____

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Key Advice/Information about Issues of Potential
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Key Advice/Information about Issues of Potential
Urgency:

Date: _____

Recorded by: _____

Key Advice/Information about Issues of Potential
Urgency:

My Medical Condition

Background information (leaflets etc.)
about my condition.



My Family, Friends and Carers

Contact details for my next of kin,
family members and friends.



Contact Details

MY NEXT OF KIN

Name : _____

Relationship: _____

Address: _____

Telephone: _____

Name : _____

Relationship: _____

Address: _____

Telephone: _____



Contact Details

Name : _____

Relationship: _____

Address: _____

Telephone: _____

Name : _____

Relationship: _____

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Contact Details

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Contact Details

Name : _____

Relationship: _____

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Telephone: _____

Name : _____

Relationship: _____

Address: _____

Telephone: _____



Useful Resources for Me and My Carers:

A place to keep information about things which might be useful to both my carers and myself.

For example:

- support groups (time, place and contact person)
- community events
- entertainment
- classes
- websites
- podcasts
- books.



Useful Resources

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Useful Resources

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Useful Resources

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Useful Resources

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Useful Resources

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Useful Resources

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Useful Resources

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Useful Resources

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In The Event Of...

becoming sick or unwell, I have the option of recording my preferences in advance regarding my preferred place of care, and my wishes regarding admission to hospital, if I have clear preferences.

If I wish, this section may also act as a place to keep very strongly held preferences, or 'advance directives to refuse treatment' such as Cardiopulmonary resuscitation.

I may also use this as a place to store any other legal agreements I choose to use, such as Enduring Power of Attorney.

(This will be completed only if I have clear preferences and I choose to record them in advance).

Important Note: It is important to inform health and care staff if I wish to record my healthcare preferences in advance. They can explain my options, give me more information (for example, the “Your Life, Your Choices” booklet, or “A Record of My Wishes”,) and help me to record my wishes appropriately. It is important to review these, to keep an up to date record of my wishes, and to communicate any changes to my health and care team, should these change.

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This healthcare Passport has been developed by the RCGP NI with input and support from the following organisations. This project was funded by the Public Health Agency (NI).

Action on Hearing Loss	Huntington's Disease Association
Accident and Emergency staff	Irish Hospice Foundation
All Ireland institute for Hospice and Palliative Care	Macmillan UK
Alzheimer's Society	Marie Curie
BMA	Motor Neurone Disease Association
Brainwave (Brain Injury Trust)	Motor Neurone Disease Care Network
Cancer focus NI	MS Society
Care of Elderly Mental Health Teams	Neurology Teams
Carers NI	NI Chest Heart and Stroke
Community Palliative Care Teams	NI Children's Hospice
Cruse	NI Rare Disease Partnership
Derry Well Woman	NI Neurological Charities Alliance (NINCA)
District Nursing Teams	Occupational Therapy Practitioners
Domiciliary Care Workers	Patient and Client Council NI
Equality Commission	Parkinson's UK
Further Education Colleges	Pharmaceutical Society NI
General Practitioners	Positive Life NI
Health Improvement (Promotion) Teams	Respiratory Nursing Teams
Hospice Staff (NI Hospice, Newry Hospice and Foyle Hospice)	Royal National Institute for the Blind
Hospital and Community Specialist Palliative Care Teams	Social Work Practitioners
	Trust Bereavement Coordinators



