How to Improve Communication Between Healthcare Professionals and Rare Disease Patients & Caregivers

A practical toolkit for healthcare communication in rare diseases

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Words from the authors

For yourself and others.

We humans are communicative beings, and communication is a very important aspect of our lives.

In medicine, communication is a crucial factor in how situations progress. Good communication, even on difficult topics such as severe disease and death, can deepen trust and strengthen the bond between humans in roles of patients, caregivers and healthcare professionals. It is a privilege for healthcare professionals to be able to discuss these important topics with patients and caregivers, and at the same time it is a responsibility.

Every communication, big or small, is an opportunity to help patients and caregivers. Good communication, even about difficult topics, can leave the patients, caregivers and healthcare professionals feeling satisfied, if not happy. On the contrary, poor communication on these topics can have lasting negative effects on both sides.

We created this toolkit booklet because many of us authors would have appreciated learning more about good and effective communication when we first started working with patients. We also know from our patients that poor communication, unfortunately, still happens today.

This short booklet brings together the key points that, in our experience and according to the literature, are most helpful for an effective communication.

We hope this booklet fulfils this purpose. We welcome your feedback and suggestions for further improvement.

The VASCERN Transversal Psychology Working Group.

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About The Toolkit

Rare multisystemic vascular diseases encompass a wide range of clinical manifestations. These diseases can have either germline or somatic mutations as their genetic basis.

Prevalence varies greatly: for example, Hereditary Haemorrhagic Telangiectasia (HHT) is a relatively frequent rare vascular disease, affecting approximately 1 in 5,000 people. However, other vascular diseases are extremely rare.

Even within one specific disease, the effect on patients' daily life can differ significantly. Some patients may live with the disease without it debilitating them, while for others, it can be severe, disabling, and in some cases, even life-threatening.

When a healthcare professional communicates with a patient affected by a rare multisystemic vascular disease, it can be difficult to know how to address important aspects as a result of the rarity and great variability among the diseases and patients.

Despite there being no perfect way or time for a healthcare professional to deliver difficult news, there are certainly some communication issues to consider, and pitfalls to avoid. To support more empathetic and effective communication, this guide was developed by the VASCERN Psychology Transversal Working Group to help improve communication between healthcare professionals, patients and caregivers. In this document, a practical role play activity is presented as a method of improving this type of communication.

For more information on the diseases covered by VASCERN, as well as additional resources, please refer to the annexe at the end of this document.

01

Role Play & Communication

This Toolkit introduces **role play** as an effective method to improve communication between healthcare professionals, rare disease patients and caregivers.

The role play involves healthcare professionals and medical students taking on **specific roles in simulated scenarios that reflect real-life challenges**. For example, one person may play the role of a patient receiving difficult news, while another takes on the role of the doctor delivering it.

These structured simulations allow participants to practise communication skills in a safe environment, reflect on their responses, and receive feedback. The goal is not to "perform", but to **explore and learn**.

In the proposed role plays, particular attention is given to **how emotions are handled, how medical information is communicated and how the role play is being experienced** by patients and caregivers on one side, and healthcare professionals on the other.

1.1 Communicate essential medical information

When communicating essential medical information to a patient, it is important to consider factors such as their age, condition, emotions, context, etc. Below is a summary of common communication mistakes, along with recommendations to help avoid them:

Common mistakes 	Recommendations 
Giving the patient medical information without an introduction.	Welcome the patient, introduce yourself, and explain the purpose of the conversation and the time you have available.
Providing too much information without giving the patient enough time to process it.	Space out the medical information given, to allow the patient time to process it and ask questions.
Using medical jargon or language not adapted to the patient's level of understanding, making it difficult for them to manage the diagnosis.	Use clear, everyday language to make sure the patient understands the diagnosis, how to manage it, and their responsibilities.
Giving information that contradicts current consensus or published evidence.	Stay updated and communicate any uncertainty in a transparent manner.
Sharing all and, perhaps, unwanted information.	Check how much information the patient wishes to receive, since every patient is different.
Speaking only to the parents, even when the child with the disease is present.	Talk to both the parents and the child, and adapt the information to the child's age and understanding. For babies or very young children, focus on supporting and informing the parents.
Not taking into account the patient's experiences, attitudes, beliefs, emotions, cultural background, or perception of the disease.	Share information with empathy, consider the emotions or feelings of the patient (this does not mean that you have to mirror the same emotion as the patient).
Not acknowledging the emotions and reactions of parents when a child is diagnosed	Help the child to understand the emotions their parents may express during the consultation and what these mean.

1.2 Common mistakes in communication in more detail

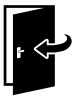
I. Environment & Setting

Be mindful of the environment and setting when communicating with a patient. A noisy or distracting environment affects communication negatively.

Common Mistake

- *A doctor explains a diagnosis while the phone rings repeatedly and people knock on the door.*

Recommendation



Minimize interruptions, and create a calm space: "Let me close the door so we can talk without distractions."

*Use a **"Do Not Disturb"** sign on the door to signal when a sensitive or important conversation is taking place. Redirect phone calls if possible.*

II. Information Overload & Clarity

Doctors risk providing too much information without checking how much information the patient wants and if the patient understands the information given.

Common Mistake

- *A long, detailed explanation of the condition might leave the patient confused and overwhelmed.*

Recommendation

The explanation should be adapted to what the patient knows or doesn't know about the disease

Similarly, using complex medical jargon can create a barrier and generate misunderstanding.

Common Mistake

- *Instead of saying "You have an idiopathic condition"*

Recommendation

Translate it into simple language that the patient can understand.

Conflicting or outdated information can confuse and frustrate the patients.

Common Mistake

- *A doctor says: "Bone fractures should always be treated by immobilisation in a plaster cast", contradicting the current guidelines.*

Recommendation

Stay updated and communicate certainty transparently: "Based on the latest research, this would be the best approach."

III. Personalising Communication

Not every patient wants the same level of detail. Some prefer summaries, while others prefer an in-depth explanation.

Common Mistake

- *The doctor spends a long time explaining complex disease mechanisms, while the patient only wants to know the next steps in their treatment.*

Recommendation

Ask the patient how much detail they prefer: "Would you like a detailed explanation, or just start with the key points?"

IV. Active Listening & Patient Involvement

A rushed consultation can make patients feel unimportant and insecure. The doctor looking at the clock, interrupting, or assuming they already know their patients' concerns can damage trust.

Common Mistake

- *A patient describes their symptoms, but the doctor interrupts with a premature diagnosis.*

Recommendation

Encouraging questions is also key. Instead of closing with "That's all", say: "Do you have questions for me? Is there anything you would like me to repeat or explain in more detail?"

Long diagnostic journeys often affect how patients perceive their condition.

Common Mistake

- *A doctor finally gives a diagnosis but says: "At least we have an answer now", dismissing months of patient frustration.*

Recommendation

"I know this has been a long journey for you, and now we know what your diagnosis is. This will help us understand your symptoms and further treatment options."

V. Empathy & Emotional Awareness

Dismissing concerns or giving false reassurance can lead to mistrust.

Common Mistakes

- *A patient expresses worry about a symptom, and the doctor says: "It's probably just stress", without further investigation.*
- *A doctor bluntly states: "Your test results show a malignancy."*

Recommendations

Validate concerns before offering reassurance: "I understand your worry. I don't think it is linked to your condition, but let's run some tests to be sure."

Instead, say: "I know this is difficult. Let's go through this together."

VI. Paediatrics

Ignoring the child in paediatric consultations can make the child feel excluded.

Common Mistake

- *A doctor speaks only to the parents: "Mum and Dad, here's what we need to do."*

Recommendations

- *Address both the child and the parents: "Hi Anna, I know you've been feeling sick. Let's talk about how we can help you feel better."*
- *Create a link between the child and the parents: "It seems your parents are worried about your health. We are going to help you and your parents to make you as fit as possible".*
- *Consider when the child should be present for the consultation. It might be a solution to divide the consultation into two parts: one with the child present, and one with the parents only: "Do you have any more questions, Anna? Otherwise, I suggest you go with the nurse and play outside while I talk to your parents for a bit. You will come back later, and we can see if you have any more questions."*

VII. Shared Decision-Making

Parents, adult and teenage patients should be involved in decision-making.

Common Mistake

- *A doctor prescribes medication without discussion.*

Recommendation

Instead, say: "Here are two treatment options. Let's discuss what could work best for you."

Summary: How to Improve Communication

Step 1

Introduce yourself and set expectations, including the time frame for the consultation.

"I'm Dr X. Let's go over your concerns together."

Step 2

Adapt communication to the patient's needs.

"How much do you already know about this condition?"

Step 3

Break information into clear sections.

Diagnosis → *Treatment Options & Prognosis* → *Next Steps*

Step 4

Encourage questions & check understanding.

- *"Does this make sense to you so far?"*
- *"Could you tell me in your own words what we have been talking about so far?"*

Step 5

Acknowledge emotions & offer support.

"I know this is a lot to take in. We'll work through it together."

Step 6

Summarize, confirm next steps & check for any remaining questions.

- *"So, just to recap, we will start with X, and we will make a new appointment. Does that sound good to you?"*
- *"Do you have any other questions or is there anything that's still unclear?"*

1.3 How to deal with lack of time

Limited time is often a problem in clinic, but there are different ways to deal with it. What is important is to focus on the patient.

Below are some possible ways to handle such situations. You may use the following or similar wording when speaking with a patient:

> *"What we are going to talk about today needs time. As time is limited, we will make the most of it. Today we have XX minutes, and I would like to go over the most important points with you. I would also like to tell you about additional resources that are available, such as online links, brochures, and the possibility to meet other health care professionals, like psychologists, nurses, or social workers."*

> *"I know that it might be a lot to process, but we will make another appointment, so you will have time to think about what we have discussed today and we can go through any questions you might have. If something comes up in the meantime, you are of course welcome to contact us, and we can address your questions or guide you towards other resources. Is that okay for you?"*

1.4 What to do if you think the patient may be depressed or suicidal

It is normal for a patient to be sad and distressed when receiving difficult news. Reassure the patient that their reaction is understandable.

If you are concerned that the patient might be depressed or suicidal, tell the patient that you are worried for them. You can say:

> *"I can see that you are very affected by this. I need to know if you are thinking of harming yourself."*

If the answer is yes, offer psychiatric support.

If the answer is unclear, or the patient declines help, say:

> *"Please remember that we are always here for you. The colleague on call might be busy, but someone will help you."*

If you believe the patient is at risk, you can suggest a safety agreement:

> *"I'm worried you might harm yourself. Can you promise not to do so until our next appointment?"*

If you doubt the patient can keep this promise, do not let him or her leave without seeing a psychiatrist.

02

How to Set Up a Role Play

2.1 Practical Instructions

To ensure the optimal running of the role play workshops, we advise that they are organized under the supervision of a group of persons experienced in the field of healthcare consultations and diagnostic announcements, such as senior doctors and/or psychologists, who should lead the discussion and the final debrief.

I. Technical equipment required

- Recording device/smartphone
- Computer/laptop
- Video projector

II. Organization of the role plays

Form groups of 4-6 persons	**For each group, the supervisors define and assign the different roles as follows:** • 1 person playing the doctor • 1 person playing the patient (adult or paediatric) • Optionally, 1-2 persons playing the patient's relative(s) • 1 person in charge of filming the role play using a smartphone • The rest of the group will observe
Give instructions to the participants	• Take all the doctors out of the room and inform them about their attitude and concern in the role play. Remind the doctors that the aim in the role play is to focus on the communication, not whether the medical information provided is 100% accurate. • Take all the patients/relatives out of the room and inform them about their attitude and concerns in the role play. • Do the above for each new role play

You can use one of the following **potential constellations:**

- Doctor + autonomous patient (with or without a relative)
- Doctor + non-autonomous patient (child, elderly person, etc.) + relatives (parents, siblings, partner, etc.)

You can define how the participants should play their role, choosing from the following list of **possible attitudes:**

- Confident/stressed doctor
- Teenage patient who doesn't care about the diagnosis
- Grumpy/confrontational patient
- Confident and well-informed patient

You can define the scenario using one of the following **potential tasks (focus on communication regardless of the scenario):**

- The doctor has to give the patient information about a diagnosis, communicating the main disease manifestations and related potential complications.

Options:

The diagnosis can be a first-time diagnosis or one already known to the patient.

Example: Telling the patient for the first time that he has X (e.g., HHT).

The severity can range from mild to severe or potentially life-threatening.

Example: Telling the parents that the child may have had a potentially fatal bleeding.

- The doctor has to inform the patient about a necessary surgery, and to ask for informed consent.

Options:

The intervention can be a minor surgery or a major intervention.

Example: Telling the patient/parents that the patient/child needs urgent surgery.

Let the groups have sufficient space for the activity	Each group should have its own physical space, separate from the other groups.
Start the role play	The doctor welcomes the patient (and relatives) and starts the dialogue. Each role play should be about 5 to 15 minutes long.
Debrief within each group	After each role play, the supervisor discusses with the group how it was experienced, what went well and what was difficult, and how it can be improved.

Bring all groups together and share experiences from the role plays	The supervisors choose video clips to show and discuss with all the participants. After multiple role plays, leave time at the end for the large group to evaluate and reflect on their experience, and what they learnt from the role plays: “Has this provided new insights? Were some scenarios more difficult than expected? What improved the communication?”

2.2 Examples of possible scenarios

You will find below some examples of possible doctor-patient communication. These examples describe situations involving rare vascular diseases. You can use them as a source of inspiration, or create your own according to your expertise.

EXAMPLE 1 - GENETIC DIAGNOSIS COMMUNICATION: THE PATIENT ALREADY KNOWS ABOUT THE DISEASE

Patient: Isabella, 22 years old, Female

Isabella is a young pre-symptomatic patient who has only experienced some non-specific symptoms. Several members of her family have a genetic disease, including her mother, a few aunts, and cousins. She voluntarily decided to undergo genetic testing, and the results have now come back positive. She has the same mutation as her mother.

The patient is a little anxious. She is young and does not have children.

The doctor has to communicate the diagnosis and should explain the risk factors, the future follow-up visits, and, if the patient wishes, the reproductive options available.

EXAMPLE 2 - RARE GENETIC DIAGNOSIS COMMUNICATION: THE PATIENT DOESN'T KNOW ABOUT THE DISEASE

Patient: Albert, 64 years old, Male

Albert, 64 years old, goes to the Accident & Emergency (A&E) department with symptoms that can be attributed to a rare genetic disease. The patient has no risk factors, but reports that he has always suffered from headaches, which have never been examined and are currently managed with pain medication. After examination, the doctor decides to run genetic investigations.

- The patient tests positive, and the doctor has to announce the diagnosis.
- The patient is afraid of the possibility of genetic transmission, as he has two children (aged 37 and 32). He wonders if and how he should inform his children.

EXAMPLE 3 - RARE GENETIC DIAGNOSIS COMMUNICATION

Patient: Anna, 42 years old, Female

Anna, 42 years old, goes to the Accident & Emergency (A&E) department, reporting symptoms that may be connected to a rare disease. The A&E doctor decides to test the patient to confirm the suspected diagnosis. The patient must then be informed about the rare disease.

- The doctor has to announce the diagnosis.
- The patient is scared and asks what could happen to her. She has a low socio-economic status and is worried about her children.

EXAMPLE 4 - RARE GENETIC DIAGNOSIS COMMUNICATION: PAEDIATRIC CONSULTATION

Patient: Eric, 8 years old, Male

Eric is an 8-year-old child who comes to the consultation with his mother, Maria, and his father, John. Eric goes to school and loves reading and playing football. He has been suffering from symptoms that make the doctor suspect a rare genetic disease.

Maria (the mother) has always come to the consultations with Eric and is worried.

When the doctor meets John (the father) for the first time, he suspects that the father might also have the same disease.

03

Additional Resources

For Rare Multisystemic Vascular Diseases

Marfan, Loeys-Dietz Syndrome https://vascern.eu/group/heritable-thoracic-aortic-diseases-2/		**Osler-Weber-Rendu disease** https://vascern.eu/group/hereditary-hemorrhagic-telangiectasia-2/	
Vascular Ehlers-Danlos Syndrome https://vascern.eu/group/medium-sized-arteries-2/		**Cadasil, Moyamoya** https://vascern.eu/group/neurovascular-diseases-neurovasc-wg/	
Paediatric & Primary Lymphoedema https://vascern.eu/group/pediatric-and-primary-lymphedema/		**Vascular Anomalies** https://vascern.eu/group/vascular-anomalies/	

For Communication

JAMA Communicating Medicine https://jamanetwork.com/journals/jama/fullarticle/2814800		**Delivering effective messages** https://jamanetwork.com/journals/jama/fullarticle/2814799	
Strategies to improve medical education https://jamanetwork.com/journals/jama/fullarticle/2812877		**Inoculation to resist misinformation** https://jamanetwork.com/journals/jama/fullarticle/2818667?resultClick=1	
SPIKES protocol https://pubmed.ncbi.nlm.nih.gov/10964998/		**Delivering bad news** https://pmc.ncbi.nlm.nih.gov/articles/PMC4677873/	

For Communication

Der schwierige Patient *https://www.aerzteblatt.de/archiv/186271/Der-schwierige-Patient-Kommunikation-ist-alles*		**Kommunikation im medizinischen Alltag** https://www.aekno.de/fileadmin/user_upload/aekno/downloads/Leitfaden-kommunikation-2015.pdf	
Patienten kommunikation https://www.forschung-und-lehre.de/zeitfragen/eine-gelungene-kommunikation-staerkt-die-zufriedenheit-1104		**Patienten kommunikation** *https://www.aerzteblatt.de/archiv/die-arzt-patient-beziehung-sieben-tipps-wie-sie-die-kommunikation-mit-den-patienten-verbessern-82c30f7b-39da-4cd4-af77-88bbd253ff0f*	
Erlernen Patientenkommunikation https://link.springer.com/article/10.1007/s00103-012-1533-0		**Patienten kommunikation für Moderierende** https://www.leukaemie-hilfe.de/infothek/eigene-publikationen/infoblaetter/arzt-patienten-kommunikation	
Patienten kommunikation für Moderierende *https://www.academia.edu/107231441/Patientenzentrierte_Kommunikation*			

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European Reference Network

VASCERN

Gathering the best expertise in Europe
to provide accessible cross-border healthcare
to patients with rare vascular diseases

VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million affected). These include arterial diseases (affecting the aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently comprises 48 expert teams from 39 highly specialized multidisciplinary HCPs coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris, France.

Through our 6 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG – European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realize the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

More information is available at: www.vascern.eu

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