Rare Disease Care with Compassion

A Practical Guide for Healthcare Professionals

By Team Waleed Foundation

Every patient deserves dignity. Every rare disease patient deserves understanding.

Rare diseases affect millions of people worldwide, yet many healthcare professionals may encounter only a few cases during their careers. Because these conditions are uncommon, patients and families often face delayed diagnosis, repeated referrals, emotional stress, financial hardship, and feelings of isolation.

For many families, the hospital is more than a place of treatment. It is a place where hope can either grow or disappear.

Healthcare professionals have the power to transform that experience.

Patient centered care, shared decision making, coordinated care, and respectful communication are recognized as essential quality standards for people living with rare diseases.

Every Rare Disease Patient Is More Than A Diagnosis

Before seeing the disease, see the person.

Behind every medical file is someone who may have spent years searching for answers.

Many patients have visited numerous hospitals before receiving the correct diagnosis.

Some have been told their symptoms were psychological.

Some parents have spent years fighting to convince others that something was wrong.

Some children have experienced pain that nobody understood.

When they arrive at your clinic, they deserve to be believed.

The First Five Minutes Matter

Patients often remember how healthcare professionals made them feel more than the medicines they received.

Simple actions can reduce fear.

Smile warmly.

Introduce yourself.

Sit down if possible.

Maintain eye contact.

Speak calmly.

Use the patient's name.

Allow the family to explain the complete story without interruption.

Active listening and relationship centered communication improve trust, patient experience, and clinical outcomes.

Never Say

"It is only in your mind."

"I have never heard of this disease."

"There is nothing we can do."

"You worry too much."

"This child looks normal."

Instead say

"I understand this has been a long journey."

"Thank you for explaining your concerns."

"I may not know everything about this condition, but I will learn."

"We will work together."

"Your experience is important."

Believe Parents and Caregivers

Parents of children with rare diseases become experts through years of daily care.

They know subtle changes.

They notice early warning signs.

They understand what has worked before.

Listen carefully.

Families should be treated as partners in care, not visitors to the discussion. Patient expertise is especially valuable in rare diseases where clinical experience may be limited.

Respect Comes Before Treatment

Respect costs nothing.

Do not stare.

Do not whisper.

Do not discuss the patient's appearance in public areas.

Protect privacy.

Ask permission before photographs.

Speak directly to the patient whenever appropriate.

Treat every child according to their age, not their disability.

Never allow curiosity to replace professionalism.

Give Rare Disease Patients Priority

Many rare disease patients have

• Limited mobility

• Respiratory compromise

• Skeletal abnormalities

• Chronic pain

• Fatigue

• Communication difficulties

Whenever possible hospitals should

Reduce unnecessary waiting.

Provide accessible seating.

Allow caregivers to remain with the patient.

Avoid repeated movement between departments.

Fast track investigations when clinically appropriate.

Coordinate multiple appointments on the same day.

Communication Saves Lives

Patients often travel hundreds of kilometers for specialist care.

Every consultation should end with clear instructions.

Explain

Diagnosis.

Current condition.

Treatment goals.

Possible complications.

Emergency warning signs.

Follow up schedule.

Medication instructions.

Use simple language.

Confirm understanding before discharge.

Provide written information whenever possible.

Coordinate Care

Rare diseases often involve multiple organs.

Patients may require

Pediatricians.

Geneticists.

Orthopedic surgeons.

Neurologists.

Cardiologists.

Pulmonologists.

Physiotherapists.

Occupational therapists.

Speech therapists.

Psychologists.

Nutrition specialists.

Social workers.

One healthcare professional should help coordinate care whenever possible, reducing confusion and improving continuity.

Shared Decision Making

Do not make decisions for patients.

Make decisions with patients.

Discuss

Benefits.

Risks.

Alternatives.

Costs.

Expected outcomes.

Quality of life.

Families should have time to ask questions.

Treatment decisions should reflect medical evidence together with patient values and preferences.

During Hospital Admission

Assign a consistent medical team whenever possible.

Review previous medical records before repeating tests.

Keep communication between departments clear.

Update families regularly.

Explain delays honestly.

Respect cultural and language needs.

Never leave families wondering what happens next.

Pain Is Not Always Visible

Many rare disease patients live with chronic pain.

Do not underestimate pain because the patient smiles.

Assess pain regularly.

Use validated pain assessment tools.

Treat pain promptly.

Refer to pain specialists when required.

Care For Emotional Health

Living with a rare disease affects the whole family.

Parents experience anxiety.

Siblings may feel neglected.

Children may fear hospitals.

Offer reassurance.

Encourage counseling when needed.

Recognize caregiver fatigue.

Psychosocial support is an essential component of rare disease care.

Learn Continuously

No healthcare professional can know every rare disease.

That is acceptable.

Refusing to learn is not.

Read current literature.

Consult specialists.

Work with multidisciplinary teams.

Use trusted clinical resources.

Connect with patient organizations.

Interprofessional education improves confidence and quality of care for rare disease patients.

Emergency Department Recommendations

Maintain a high index of suspicion.

Review previous emergency plans.

Contact the patient's specialist when needed.

Avoid assumptions.

Document baseline functional status.

Monitor carefully for rapid deterioration.

Recognize that even common illnesses may affect rare disease patients differently.

The Team Waleed Foundation Principles

At Team Waleed Foundation, we encourage every healthcare institution to adopt these principles.

Listen before you diagnose.

Respect before you treat.

Believe before you doubt.

Educate before you assume.

Collaborate before you decide.

Support every family.

Protect every child's dignity.

Treat every patient with compassion.

Never let rarity become a barrier to quality healthcare.

A Message To Every Healthcare Professional

Your knowledge heals.

Your kindness heals.

Your patience heals.

Your respect heals.

A rare disease may affect only a small number of people.

But to the patient sitting in front of you, your compassion can change an entire lifetime.

Together, we can create hospitals where every rare disease patient feels safe, respected, heard, and cared for.

Team Waleed Foundation

Together for Every Rare Life.