ND Waiting List Support Toolkit

Reducing distress, risk, and escalation for neurodivergent patients on long pathways.

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Important note

This resource is intended to support understanding and good practice in neuro-inclusive workplace design. It provides general guidance and does not constitute legal, medical, or clinical advice. Organisations should apply the principles in line with their own policies, regulatory obligations, and professional judgement.

A clear orientation (for healthcare and support services)

This is not a reassurance pack.
It is not a substitute for timely care.
It is not a way to ask patients to cope better with delay.

This toolkit exists because **long waiting lists are a high-risk period** for many neurodivergent (ND) patients… particularly those with ADHD, autism, AuDHD, trauma histories, or prior system harm. During extended waits, services often see:

- rising distress and crisis presentations
- disengagement or drop-off
- incomplete information at re-contact
- complaints driven by fear, not hostility

ND-safe waiting list support focuses on **predictability, clarity, and containment…** reducing threat while people wait, without requiring disclosure or emotional labour.

This toolkit should be used to **change how services hold people**, not to justify delays or shift responsibility onto patients.

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1. Core reframe: waiting is an active risk period

Waiting is often treated as neutral time.

For ND patients, waiting can mean:

- uncertainty with no anchor
- loss of control under power imbalance
- fear of being forgotten or dismissed
- constant self-monitoring ("Am I getting worse?")
- repeated re-telling when re-contact occurs

Without structure, waiting becomes **chronic threat**.

Support during waiting is a safety intervention, not a courtesy.

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2. What ND-safe waiting support is *not*

To prevent harm, be explicit.

ND-safe waiting support is **not**:

- motivational messaging
- generic wellbeing advice

- pressure to self-manage risk
- repeated "check-in" demands
- a requirement to disclose diagnosis

It *is*:

- predictable communication
- clear expectations
- honest boundaries
- accessible information
- simple containment strategies

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3. The goals of this toolkit

This toolkit aims to help services:

- reduce uncertainty and rumination
- maintain connection without pressure
- lower crisis escalation during waits
- protect dignity and trust
- support continuity when care begins

Success is not measured by positivity.
It is measured by **reduced harm and clearer re-entry**.

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4. Tiered waiting list support (design so disclosure isn't required)

Tier 1… Universal support (for everyone)

Available by default, without labels:

- clear confirmation of being on the list
- transparent explanation of the pathway
- realistic timeframes (with uncertainty named)
- predictable update schedule
- clear "who to contact if" information

This reduces anxiety without asking anyone to self-identify.

Tier 2… Optional stabilisation supports

Available on request, without diagnosis:

- written summaries of next steps
- pacing guidance for re-contact
- signposting to interim supports (non-overwhelming)
- practical containment tools (see Section 7)

Language matters:

"Support while you wait is available."
not
"If you're struggling, tell us why."

Tier 3… Risk-aware support (only when needed)

Used when there are **clear risk indicators**, not as default:

- named point of contact
- agreed escalation thresholds
- safeguarding clarity
- consent-based information sharing

Risk support must **add safety**, not increase scrutiny.

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5. Communication standards for waiting periods (non-negotiable)

5.1 Predictable updates

- set a **known update cadence** (e.g., every 8–12 weeks)
- send updates even if nothing has changed
- state clearly when the next update will be

Silence increases distress more than bad news.

5.2 Plain-language timelines

Avoid:

- "as soon as possible"
- "when capacity allows"

Prefer:

- "Current estimate: X–Y months. This may change."
- "If this changes, we will contact you."

Naming uncertainty is safer than vague reassurance.

5.3 One clear contact route

Provide:

- a single point or method for queries
- guidance on what that route *is and isn't for*
- realistic response times

Multiple routes increase confusion and repeated contact.

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6. ND-safe language for waiting list communications

Use:

- neutral, respectful tone
- short paragraphs
- clear headings
- explicit next steps

Avoid:

- minimising language ("just waiting")
- comparison ("others are waiting longer")
- pressure to be patient
- emotional framing ("we know this is frustrating" repeated without action)

Clarity reduces threat more than empathy statements alone.

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7. Containment tools for patients while waiting (optional, low-demand)

These are **supports**, not expectations.
Offer them lightly, without pressure.

7.1 What to do if distress increases

Provide a simple, written guide:

- signs that support is needed
- who to contact
- when to seek urgent help
- reassurance that reaching out will not affect position

This prevents crisis escalation through uncertainty.

7.2 What *not* to do while waiting (protective guidance)

Gently name common traps:

- repeatedly re-checking timelines
- over-consuming online information
- self-blame for delays

This normalises distress without moralising coping.

7.3 Simple grounding options (non-prescriptive)

Offer optional, non-instructional suggestions:

- keeping a brief log of symptoms or questions
- writing notes for future appointments
- identifying one or two trusted supports

Avoid:

- long self-help lists
- productivity framing
- anything that feels like homework

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8. Managing re-contact safely (when the wait ends)

Re-contact is a **high-load moment**.

ND-safe re-contact includes:

- advance notice where possible
- clear explanation of what will happen next
- options for appointment format (where feasible)
- written confirmation after verbal contact

Avoid:

- last-minute calls with no context
- expecting immediate decision-making
- bundling multiple steps at once

Smooth re-entry prevents dropout.

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9. Documentation & continuity (behind the scenes)

To reduce re-traumatisation:

- retain brief summaries of prior contact
- avoid asking patients to re-tell everything
- carry forward stated preferences (with consent)

Continuity is safety.

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10. Common mistakes that increase risk

Avoid:

- treating waiting list support as "extra"
- removing people silently
- sending frequent but content-light messages
- asking patients to justify distress
- assuming no contact means coping

Many ND patients disengage **before** they escalate.

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11. Measuring effectiveness (without surveillance)

Better indicators than "engagement" include:

- fewer crisis presentations
- clearer information at assessment
- reduced complaints driven by fear
- improved attendance at first appointment

Disclosure rates are **not** a safety metric.

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12. Organisational guardrails (non-negotiable)

This toolkit must not be used to:

- justify long waits
- deny escalation when needed
- place responsibility for safety on patients
- require disclosure to access support
- monitor behaviour or distress

If waiting support increases pressure, it is unsafe.

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13. A brief service self-check (optional)

Teams may reflect:

- Do patients know what will happen next… and when?
- Do we communicate even when nothing changes?
- Can people ask for support without penalty?
- Are our messages calming or ambiguous?

This is an orientation check, not an audit.

A closing note for services

Waiting lists are not neutral holding spaces.

They are **active periods of vulnerability…** especially for neurodivergent patients navigating uncertainty, sensory load, and past system harm.

Services that:

- communicate predictably
- name uncertainty honestly
- offer containment without pressure
- protect dignity during delay

do not make waiting easy.

They make it **safer**.

And safety during waiting reduces escalation, preserves trust, and improves care when the pathway finally opens.

Use what fits.
Adapt freely.
Design for nervous system safety first.