

## Trait → Plan Checklist for Pulmonary Rehabilitation in Alpha-1 Antitrypsin Deficiency (AATD)

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### Step 0. Patient & AATD Background

Patient initials / ID: \_\_\_\_\_

Date of birth (DD/MM/YYYY): \_\_\_\_\_

AATD genotype: ☐ ZZ ☐ SZ ☐ MZ ☐ Null ☐ Other \_\_\_\_\_

Date of AATD diagnosis: \_\_\_\_\_

Augmentation therapy: ☐ Yes (Start \_\_\_\_\_ Product \_\_\_\_\_) ☐ No

Lung function (latest): FEV<sub>1</sub> \_\_\_\_ % pred FVC \_\_\_\_ % pred SpO<sub>2</sub> (rest) \_\_\_\_ %

Smoking history: ☐ Never ☐ Ex-smoker (Quit \_\_\_\_ ) ☐ Current \_\_\_\_ pack-yrs

Occupational exposure: ☐ Dust/fumes ☐ Outdoor ☐ Sedentary ☐ Other \_\_\_\_

Physical activity / work status: ☐ Employed ☐ Retired ☐ Unemployed ☐ Student

Co-morbidities: \_\_\_\_\_

Current PR phase: ☐ Initial ☐ Mid-programme ☐ Completion ☐ Follow-up

Clinician name / role: \_\_\_\_\_ Date: \_\_\_\_\_

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### Step 1. Identify Treatable Trait(s)

Trait Category	Example AATD-specific features	✓
Breathlessness variability	Early airflow limitation, fatigue, mismatch between spirometry & perceived symptoms, flare episodes	<input type="checkbox"/>
Deconditioning / inactivity	Post-exacerbation weakness, low confidence, avoidance due to fear of effort	<input type="checkbox"/>
Psychological or emotional well-being	Low mood, frustration, hopelessness, uncertainty about future, stigma	<input type="checkbox"/>
Anxiety / stress response	Fear of breathlessness, panic sensations, flare anticipation, anxiety around O <sub>2</sub> use	<input type="checkbox"/>
Oxygen use / setup issues	Hesitancy with oxygen, tubing limits, flow mismatch, equipment unfamiliarity	<input type="checkbox"/>

Trait Category	Example AATD-specific features	✓
Pacing / energy conservation	Over-activity on “good days,” rebound fatigue, poor rest planning	<input type="checkbox"/>
Flare / relapse risk	Frequent chest infections, poor sputum clearance, augmentation interruptions	<input type="checkbox"/>
Other:		<input type="checkbox"/>
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## Step 2. Assessment Cues / Contributing Factors

*Use this section to summarise key findings that guide which Treatable Traits are prioritised. Record both objective and subjective indicators.*

### Clinical Assessments

- Pulmonary function: FEV<sub>1</sub> % predicted, FVC, SpO<sub>2</sub> (rest / exercise / recovery).
- Exercise capacity: 6-Minute Walk Test (6MWT), Incremental Shuttle Walk Test (ISWT), Step test, Sit-to-Stand.
- **Symptom scales:**
  - COPD Assessment Test (CAT)
  - Modified Medical Research Council Dyspnoea Scale (mMRC)
  - Borg Scale / Rate of Perceived Exertion (RPE) — note if > 5 at low load
  - Hospital Anxiety and Depression Scale (HADS)
- Desaturation: Oxygen saturation (SpO<sub>2</sub>) < 90 % during exertion or slow recovery > 60 s.

### Patient-Reported Indicators

- Symptom diary: fluctuations in breathlessness, cough, sputum colour/volume, fatigue.
- Activity pattern: step-count data, smartwatch or phone tracking, reported daily activity levels.
- Behavioural cues: avoidance of stairs, exercise anxiety, over-activity on “good days,” prolonged rest on “bad days.”
- Psychological state: low mood, frustration, worry about oxygen dependence or disease progression.

- Social and environmental factors: living alone, limited support, distance to PR centre, occupational triggers (e.g., dust, heat).

### Clinician Notes

Record key findings or contributing factors that influence trait selection and planning:

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### Step 3. Agreed Actions / Interventions

Domain	Example AATD-adapted strategies
Exercise & activity	Introduce gradual <i>Ramp Plan</i> ; increase duration 1–2 min/week if within RPE 3–5 and SpO <sub>2</sub> ≥ 90 %.
Breathing & pacing	Teach <i>pursed-lip breathing</i> , use “good/bad day” pacing cards, interval walking.
Oxygen management	Review O <sub>2</sub> flow & setup; supervise first exercise use; portable concentrator practice.
Psychological / emotional	Brief relaxation, reassurance, peer or psychology referral, AATD support group.
Education	Vaccination, trigger avoidance, flare plan, augmentation adherence, home monitoring.

Clinician notes:

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#### Step 4. Exercise Target / Progression Rule (Updated)

Target RPE (Rate of Perceived Exertion): 3–5

Progression: +5–10 % load or +1–2 min/week if within target range & no red flags

Frequency: \_\_\_\_\_ sessions/week

Mode:

- ☐ Walking   ☐ Cycling   ☐ Resistance bands (e.g., TheraBand)   ☐ Mixed / circuit  
☐ Continuous training   ☐ Interval training (walk–rest, step–sit, etc.)

Comments

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#### Step 5. SMART Goal Setting

*Agree one or two specific, achievable goals to guide rehabilitation and self-management.*

SMART element	Guiding question	Patient-specific goal
Specific	What exactly will you do?	_____
Measurable	How will you know it's achieved?	_____
Achievable	Is it realistic given your ability and oxygen needs?	_____
Relevant	How does this help your daily function or symptom control?	_____
Time-bound	When will you aim to achieve this?	_____

☒ Overall goal statement:

"I will \_\_\_\_\_ by \_\_\_\_\_ (date)."

Notes / feedback on progress:

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## Step 6. Follow-up / Monitoring

Review point	Indicators	Plan
2 weeks	Attendance, RPE, confidence using O <sub>2</sub>	<input type="checkbox"/> Phone <input type="checkbox"/> In-person <input type="checkbox"/> Tele-PR
6 weeks	6-Minute Walk Test (6MWT), CAT, activity tracker	<input type="checkbox"/> Continue <input type="checkbox"/> Modify <input type="checkbox"/> Discharge
Flare event	Symptom change, recovery time	<input type="checkbox"/> Restart ramp <input type="checkbox"/> Review augmentation

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## Step 7. Summary & Reflections

Main goals achieved: \_\_\_\_\_

Barriers identified: \_\_\_\_\_

Next step / referral: \_\_\_\_\_

## Appendix A – Exercise Choice Menu for AATD

Category	Example Options	Notes
<b>Aerobic (low → moderate)</b>	Walk-to-rest intervals · Step-ups (10–15 cm) · Recumbent cycle · March on spot	Gradually increase duration 1–2 min/week; monitor SpO <sub>2</sub> ≥ 90 %, RPE ≤ 5
<b>Resistance / strength</b>	Seated knee extensions (bands) · Sit-to-stand · Wall press · Biceps curl	8–12 reps × 1–2 sets; rest ≥ 60 s; slow tempo
<b>Breathing &amp; core</b>	Pursed-lip / diaphragmatic breathing · Balance + breath control	Use between aerobic sets or during recovery
<b>Pacing &amp; energy conservation</b>	“Good/bad day” cards · Alternate upper/lower tasks · Talk-test pacing	Reinforce symptom-based rest strategy
<b>Flexibility &amp; mobility</b>	Gentle stretches · Shoulder rolls · Trunk rotation	End of session or morning routine
<b>Relaxation / recovery</b>	Guided relaxation · Box breathing (4×4×4×4) · Music-assisted breathing	Helpful post-session or during flare recovery
<b>Oxygen familiarisation</b>	Adjust flow during walking · Portable O <sub>2</sub> setup · Tubing management	Reinforce self-checks and confidence

## References & Evidence Base

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4. American College of Sports Medicine (ACSM). *Guidelines for Exercise Testing and Prescription*, 10th ed., 2021.
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## PR-for-AATD Co-Design Toolkit

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