The First Week Packet

For the days after FTD enters your life.

This is for the moment when everything feels too big and you need somewhere to begin.

You do not have to understand the whole disease today. This is a small packet for getting through the first week with a little more steadiness: what changed, who needs to know, what needs to be safer, and what you may want in front of you later.

START SMALL

Print it. Use a pen. Cross things out. Leave blanks. This is not a test and it is not a care plan. It is a calmer place to put the first pieces.

INSIDE

HOW TO USE IT

Pages 3 and 5 are meant to be printed more than once — one log sheet per incident, one cover sheet per folder. Pages 2 and 4 you fill in once and revisit.

If you need to talk to someone who knows FTD: the AFTD HelpLine is 866-507-7222. If you are in a mental health crisis in the US, call or text 988.

The first week, in three passes

Not everything — the first pass. These are the things that are easier to do before everyone is exhausted, and much harder to do in a crisis.

IF YOU ONLY DO ONE THING

Write down what changed, while the details are still sharp. Almost everything else on this page gets easier once something is written down.

TODAY

- [ ] Write down what changed, before the details blur.
- [ ] Tell one trusted person what is happening, and what help would actually be useful.
- [ ] Put insurance cards, IDs, medication bottles, and key paperwork in one place.

THIS WEEK

- [ ] List current doctors, specialists, medications, and upcoming appointments.
- [ ] Choose one family point person for medical calls and records.
- [ ] Sign the release that lets that person receive information.

  Ask each clinic for their records-release or HIPAA authorization form. Without it, the point person can be told nothing — this is the step families most often miss.
- [ ] Look honestly at driving, cooking, wandering, stairs, medication access, and falls.
- [ ] Ask separately about firearms, account access, scams, and impulsive spending.

  Judgment and impulse control change early in FTD. These two escalate faster than anything else on this page, and both are far easier to handle before a crisis than after one.
- [ ] Find one FTD-specific support contact before you need it urgently.

BEFORE THE NEXT APPOINTMENT

- [ ] Bring the what-changed log, even if it is only three lines.
- [ ] Ask which specialist should be leading care from here.
- [ ] Write down one ordinary detail you may want to remember later.

A SENTENCE TO KEEP NEARBY

Do the next useful thing, not the entire future.

What changed

Fill one in after an incident, appointment, fall, argument, unusual behavior, medication change, or any moment you are afraid you will forget. Specific notes help doctors, family, paperwork, and your own memory.

PRINT AS MANY COPIES OF THIS PAGE AS YOU NEED — ONE SHEET HOLDS TWO ENTRIES.

ENTRY

DATE / TIME

WHERE IT HAPPENED

WHAT HAPPENED

WHAT WAS DIFFERENT FROM USUAL

WAS THERE A SAFETY CONCERN

WHO NEEDS TO KNOW

CONTEXT — MEDICATION, SLEEP, STRESS, FOOD, ALCOHOL, CHANGE IN ROUTINE

ENTRY

DATE / TIME

WHERE IT HAPPENED

WHAT HAPPENED

WHAT WAS DIFFERENT FROM USUAL

WAS THERE A SAFETY CONCERN

WHO NEEDS TO KNOW

CONTEXT — MEDICATION, SLEEP, STRESS, FOOD, ALCOHOL, CHANGE IN ROUTINE

Care circle

The people who can help before a crisis decides for you. Fill in what you can; leave the rest for later.

PRIMARY CONTACT

BACKUP CONTACT

DOCTOR / CLINIC

PHARMACY

NEIGHBOR OR NEARBY HELPER

LEGAL / FINANCIAL CONTACT

EMPLOYER OR HR CONTACT

Leave, benefits and disability paperwork start here.

WHO HAS A KEY

Who can get in if nobody answers the door.

PEOPLE WHO SHOULD BE UPDATED

PEOPLE WHO SHOULD NOT BE UPDATED

QUESTIONS TO BRING TO THE NEXT APPOINTMENT

- [ ] What symptoms should we track from here?
- [ ] What changes would make this urgent?
- [ ] Which specialist should be leading care — neurology, behavioral neurology, someone else?
- [ ] Who do we call after hours — and who do we call when the emergency is behavior rather than the body?
- [ ] What paperwork should we start now, while there are still more choices available?
- [ ] What safety changes should happen first?
- [ ] What support exists for the family, not only for the patient?

Emergency folder cover sheet

Keep this with the papers someone would need if you were not there to explain everything. A folder, the fridge, a shared family drive. **Print a fresh one whenever something changes.**

FULL NAME

DATE OF BIRTH

DIAGNOSIS / SUSPECTED DIAGNOSIS

PRIMARY DOCTOR

ALLERGIES

PREFERRED HOSPITAL

INSURANCE

PHARMACY

EMERGENCY CONTACT

BACKUP CONTACT

CURRENT MEDICATIONS AND DOSES

WHAT THIS PERSON MAY NOT BE ABLE TO TELL YOU

FTD can affect language, judgment, and a person's awareness of their own symptoms. They may not report pain, may not recognize that anything is wrong, and may respond to stress in ways someone outside the family may misunderstand. Whatever you write here may be the only version a paramedic or nurse ever gets.

ANYTHING ELSE SOMEONE WOULD NEED TO KNOW

ONE LAST THING

This packet will not make FTD simple. It is not simple. But it may help you walk into the next conversation with a few more facts, a little less panic, and something solid in your hands.

AFTD HelpLine 866-507-7222 · **Crisis line (US)** call or text 988 · More at nxttoftd.com