

## *Time*

Kristen Kehl-Floberg

*“All we have to decide is what to do with the time that is given to us.”*

*-J.R.R. Tolkien*

A person's use of time is a code for meaning and ability. It isn't the full text of a person's choices and needs, but it cracks open the conversation. To an occupational therapist, time is a factor, a context, a resource, a metric, and a performance dimension.

At my first visit with a person, I ask some variation of “how do you spend your time?”

My interest is two-fold; I get info about their unique identity and life course so I know what my skilled intervention needs to support, and they get insight into how well their present reality matches their desire. People whose lives have proceeded at a steady clip until now (such as those with traumatic injuries, recently-diagnosed cancer or degenerative disease, a parent of a newborn or young child with a disability, or orthopedic surgeries) name complex things like working, family routines, social and community life, spare-time pursuits, and so on. The nature of their need for therapy is abrupt, so often they say that being well and healed means a complete return to living as they'd just described.

But for those of us who are chronically ill, time is enfolded in loss. Incremental accumulation of imperceptibly small changes add up to perceptible disability, but often we miss that anything has changed when we're in the thick of it. We just bravely endure. Chronic illness, including years of caregiving for a family member with it, can cause a rational person to

simply ignore their well-being and sense of options. For these situations, I follow-up: “How would you like to spend your time? Is there anything you used to do, or want to learn or try, that you can’t do because of your symptoms?” Asking about time use is a potent charge. Some people have lived for so long with so little choice that contemplating this question is painful. When using the question, I’ve learned to genuflect to its profound implications. I want it to be productive, not terrifying.

The codified realities hidden within time use are especially dramatic for people with addiction. Since the brain becomes dependent on the chemical(s) in question, subconscious valuations of how one spends one’s time are always biased in favor of using. As addiction progresses, it shapes more and more of the places, routines, relationships, and certainly time expenditures that a person chooses. Patterns of daily life become glued in place by the sureness of access to the drug; disrupt either the access or the pattern, and a certain amount of chaos ensues.

One approach in addiction treatment is to rebuild patterns of occupation around non-using. The Odyssey House Rehabilitation Center in New York City uses marathon training as a rehabilitation technique because it replaces using with another activity involving hours of daily practice, health monitoring, incremental progress toward a goal, and euphoria following hard work. It’s a brilliant choice for those whose bodies are able to tolerate it; it reengineers daily routines around something health-promoting and dopamine-boosting. It uses occupation as the means (the therapeutic modality or activity) and the end (a healthy routine that doesn’t involve using, buttressed with personal accomplishment and a new way to feel pleasure).

L.L. (pseudonym)

On the general medicine service of an urban hospital, I received a referral for a man in his early 50's admitted with a cluster of things that go wrong when you neglect to eat, drink, and void promptly. His history and physical note documented hypokalemia, hypoglycemia, an acute kidney injury, and altered mental status; toxicology results were positive for cocaine and heroin intoxication. He was documented as homeless, having told some staff he stayed with this sister, others that he lived with a roommate, and still others that he was "looking for a place"... all of which may have shared some percentage of the whole truth. He'd been found in the street, soiled and unresponsive, with decreasing respiration and heart rates. He was intubated on the ride to the hospital, stayed in the ICU for a few days and treated with medications that eased his withdrawal symptoms. He had been at the hospital for nearly a week. His labs appeared to have nearly reached normal parameters, with the exception of blood glucose which kept reading too high, in the mid 200's. The MD's referral for OT and PT stated "weakness" and "decreased ADL independence." And I read the H&P once more, then read the H&P from his previous two admissions. Documentation on patients who come back often sometimes misses change over time, as staff begin to take only a cursory "this-guy-again" attitude.

When I entered, he was in the bed nearest the door in a dim double-occupancy room crowded with the other patient's visitors. His curtain was drawn around his bed, letting little light through. His brown complexion was ashen with anemia and dead skin, his finger nails long and cracked. He wasn't obviously weeping, but his eyes were wet as if floating in goo, held back by weary squints. He lay fidgeting and remote. The IV pump beeped and his TV aired something about motorcycles to no one in particular. He had no visitors. He looked uncertain.

After introductions and verifying I had the right person, I told him OT had been ordered “to help you recover from this hospital stay and get back to living your life.” He wheezed and chuckled.

“I don’t think that’s what you want.” His consonants were soft for want of a few teeth, his voice thin.

After a pause I clarified: “We want you to be well, and strong so you can live as you want to.”

What OT really does to achieve this is so elemental it can be invisible. Our interventions pursue breakdowns in every parameter of Doing. Like molecules of air, they move into the space between us and our works, deeds, friends, meals, outings, housework, hygiene, pleasure, success - and exchange within us, a give-and-take of our course through the day. Its difficult to describe; we can’t even settle on an all-encompassing description, because there isn’t an all-encompassing approach for all people. The goal is always a full life. Concrete examples risk over-simplification and losing a person’s interest, but concrete is best for an introduction. This is first-date-level complexity. So I offer:

“Your doctors mentioned that you’re having trouble caring for yourself, like eating regular meals and cleaning up, and that you’re experiencing weakness in your muscles.” (Notice I avoided the phrase “taking showers”, because poor hygiene carries stigmas of incompetence and dereliction; similarly “you’re weak” colloquially describes willpower as well as muscle strength.)

I go on, moving about the room to ready it for his movement: “PT came in earlier to test your strength and stamina, and I’ll look at that too. Mostly, I’m here to see if your illness is

making it harder for you to do your daily routines, and teach you new ways of doing things if you'd like to try. Might mean setting up your space or planning your day a little differently, trying a new way to get dressed, learning short cuts, or setting up reminders for yourself. I'll work with PT, your doctors, and you, to recommend a good next step in your recovery."

"Rehab?" He asks.

"Could be rehab, certainly." I said, without thinking. Physical Rehab professionals tend to forget that "rehab" has two meanings to certain people.

To ground our visit in simplicity, I ask "Is there anything you'd like to do to get ready for the day? Did you have a chance to brush your teeth?" Stupid question, asked in automatic inattention as I fussed with the bed settings.

"Don't have any," he grinned, "but I do have to pee."

Tremulously, but without help, he sat at the edge of the bed, took a hospital-issue cane off the bedrail, and bent his head. He stood, swayed; I put a hand on his back, then countered his sway like a dance partner when I felt him lean too far.

"Might need a hand" he said. "Don't have my feet yet." I placed a gait belt around his chest.

"I'm right here with you. I won't lift you with this, it just gives me something to hold if you start to lose your balance.

"M OK." he girded. He reached the open bathroom door but passed it, heading into the hallway.

"Where are you going?"

“Toilet.”

“Toilet’s not out there,” I said. “Do you wear glasses? I’m sorry, I forgot to ask.”

“No” he said, and halted, swayed again, and looked ahead, indecisive. I noted his confusion when facing the every-day issue of navigating a new environment, then prompted “Look behind yourself. It’s in your room.”

He shuffled, fumbled with his cane, turned around, and stumbled over his own feet into the bathroom. He found the toilet and sat on it facing backward, leaning an elbow on the plumbing.

This was quite unique. I wondered why, and for how long, he’d used this position. Is it more comfortable? Does he fall off? Is he having trouble interacting with objects in his environment properly, is this new, and has he been using other objects oddly? How does he straddle the stool with pants around his knees or ankles? As he wiped, he got his hands dirty; I helped him clean up, changed my gloves, then watched him lean on the plumbing, scoot backwards off the toilet seat, and stand up in segmented fashion.

“That’s how I do it.” He smiled toothlessly, perhaps noticing curiosity in my expression. His satisfaction was endearing despite the fact that in real life (absent a helper) there would now be poop on his bottom, his hands, the toilet seat, and pretty soon his pants.

“Very creative!” I affirm. “I have just one question: what do you do with your pants?”

“Don’t know.” He shrugged, “Hain’t seen my pants since I came in here.”

Perhaps he’d misunderstood my tense, or didn’t hear well. I added, “When you sit on the toilet like that... like it’s a motorcycle? Do you take your pants all the way off first?”

He mumbled “I don’t need...” something-something, then moved to leave the bathroom. I reminded him he’d gotten his hands dirty, and he stopped at the sink for a very cursory rinse. I helped him scrub with soap and changed my gloves again as he leaned on the sink.

“I’m tired” he said.

“I bet you’re tired. Its been a long week.” I realized I shouldn’t have said that; it gave clues. Curious to see if he’d pick up on them, I asked anyhow: “Do you remember how long you’ve been here?”

“About three days.”

“Do you remember why you came?”

“Couldn’t walk...”

A pause.

“Have the doctors told you what they treated you for?” I asked.

“Nah” he said. Then abruptly he tacked and quietly said: “Too many drugs.”

“Yeah, that’s my understanding.” I said conversationally, trying not to betray a sudden sense that I had no idea what to do next. Addicts don’t generally tell strangers they use too many drugs. Then again, they generally don’t have strangers watch them poop.

I decided to proceed with compassion. Tenderly, and with explicit disclosure of curiosity, I asked more questions as I steadied him back to his bed. I asked if he had trouble getting on and off the toilet, and whether he had help to clean himself up, shower, cook, dress, or drive. His replies were not always detailed, but always practical. His sister had been helping him but became frustrated and stopped. His awareness of need for assistance was incomplete,

but he also had some insight into his limitations, such as insisting he never tried to drive because he felt he would pass out and get in a wreck. (Only when I asked did he admit he'd lost his license years ago). As for those pants, he said he rarely dressed his lower body any more, or wore oversized sweat pants, because his only viable veins (that he could see) were in his legs. He had devised the backwards toilet approach while attempting to go through withdrawal at home. He could move from puking to defecating without turning, which avoided stimulation to the vestibular and visual integrating pathways that they couldn't reconcile, causing him to fall.

“You're very creative.” I said again. “And, correct me if I misunderstood you, but it sounds like you'd like to get sober?”

With crystalline earnestness and vulnerability, he said “Yes, I try. I try.”

A picture had emerged of how time feels for this man, of the course of his days and nights. Time was a thing to endure, a ransom paid before the brief absorption of it into the briefest euphoria... and now, a thing to run from, because if he sensed time it was because he was coming down, and that meant he needed to use again as soon as possible. It was not an asset. All his brain's resources, attention, intention, and action were plied toward satisfying addiction; so, then, was all this time. For his addicted brain, everything in his life was organized and executed to protect and maintain access to substances.

But there before me, as well, was a person with a living soul. A person needing love, with a point of view, with values. What would occupy his days, if not this? Here in the hospital I can't deliver many opportunities for this process of discovery, but I can ask:

“So, here's a question: What would you do with your time if you didn't feel you needed to use?”



The air left the room. He was suddenly still, looking at the wall, his wet eyes wetting more. It seemed as he sat motionless at the edge of the bed, he was at the edge of a chasm, yearning for something out of reach in mid-air. Finally he smiled and shook his head. "I don't know." He shook his head again, as if in disbelief. After another moment of quiet, he said "Ma'am, you just did me hard." He looked down at his yellow slipper socks, swaying unevenly, breathing unevenly, and fidgeting. Two drops fell on his gown. I reached a tissue from his table. I sat next to him in quiet. After a minute he said "I can't talk no more about that right now."

Although we proceeded for a few more minutes talking about his concerns with his balance and hygiene, getting Medicaid, and ADA transit options, it was clear my time with him had already ended. I suggested that, because his balance was such a challenge and he was having a hard time with spatial problem solving, a stay at a rehabilitation center for more therapy before going home was advisable (with the caveat that we'd have to find one with a Medicaid bed available). He was agreeable, though lukewarm. A glimmer of interest came into his eyes when I mentioned he could go to the public library in the future for some programs and support, but even as he said "I like to read..." it faded. Ever so gently I said "reading could be one thing to fill your time, and its free at the library." He nodded. But he wasn't really there with me.

I'd felt a rush from the confidence he'd placed in me (and was in danger of seeing myself as totally critical to his recovery, of seeing him as needing me desperately), then a crash when I knew I'd pushed too far. I got him settled in bed, then started entering some of my assessment on the room computer. After a few minutes I start my closing:

"We talked about a lot today. What would you like to focus on, so I can plan ahead in case I see you again before you leave? I can also let the rehabilitation facility know."

“Go to the library” he said without hesitation; “Not fall.” Then, “Get clean.”

“Ok, that’s quite a to-do list. How about we look at your balance some more, try different ways to get dressed and cleaned up that feel safer to you, and learn about some community options. Can I tell the social worker here you’d like to be referred to an addiction specialist?”

A dark cloud gathered. His expression fought with itself. He looked nervous.

I continued “I can just ask them to talk to you about your options. You can take or leave what ever you’d like. Its really just a starting point.” A pause. “In the mean time, lets you and I work on the other parts of the plan.”

“OK” he sighed. I thanked him for working with me, asked if he needed anything, placed his phone and call light at his hand, unmuted the TV, and wiped off my equipment. I left him gazing at the wall, listening to his neighbor’s visitors, and not watching his TV.

Back at the nurse’s station I called the resident on his team and told him L. had expressed interest in pursuing rehab for substance dependence. “Oh, wow,” he said. “Umm, OK. I’ll talk to social work. How did that come up? I mean, he’s a little stand-offish with us.”

I told him my observations of toilet hygiene and dressing, and that this led to him revealing he’d tried to get clean on his own.

“I know about that, yeah” said the resident, “but he never wants to talk about rehab.”

“I just... asked him how he wants to spend his time.” I said. “He was distant afterwards, but still insightful. It sort of went from there. I mean, it seems like he’s open to the idea but still

struggling with it, so, you know, maybe don't run in thinking he's super excited about it. But he did say he wants to get clean, and agreed to go to a SNF for rehab for his balance and cognition."

I didn't work for a few days after that, and when I did, he'd been discharged. As I rounded on the service that morning I asked the social worker if he'd found any options for L.L.

"I didn't," he said. "There's not really anything for him, with no insurance. All the addiction specialists and D&A rehab centers are private pay."

"Were you able to get Medicaid started for him? That might at least cover some transportation, like to a peer support group."

"He declined. He said he didn't want it if it wouldn't cover treatment."

"Hmm, ok. Well, we recommended SNF for balance and cognitive impairments, did he at least get there?"

"No, he declined. They won't take him without insurance anyhow. We gave him a cab voucher, he said he was going to his sister's house."

"How did he get into the cab??" I gaped, incredulous. "Did he get a cane from PT at least?"

He was pressed for time and didn't have answers, as he too had been off the day before.

I felt like we'd lost him. He'd gotten past the mountainous barrier of withdrawal and readiness to seek help, only to be shut out by systematic chasms between mental health crises and treatments. Here was a man willing (albeit delicately) to build a whole new life, a whole new use of his remaining precious time, from the dust of his last OD. And here was a system that was somehow content to spend a week's worth of hospital resources (unreimbursed because

he didn't carry insurance) to get him "medically stable", then show him the door without any thought for whether we'd treated his disease. All the dots were there, and we couldn't connect them.

I don't know what happened to L. after that, and I never got a chance to ask him more. What ever he was doing with his time now, it wasn't coming to the hospital.