

# **“Caring-About-Caregivers” Long-Range Scenario Planning (LRSP) to 2033**

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## **Exploring Robust Strategies with Future Scenarios of Caregiving**



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## Summary of Scenarios

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### 1. Caring from a Distance

“Mike has ended up living the closest, even though Amy and his parents have always been closer. But Amy’s finding ways to stay involved, and Mike’s work is doing what they need to keep him on board.”

### 2. Designed for Living

“HEED buildings are turning places you have to be into places you want to be. Luis works out a new caregiving arrangement for his mom, but he’s still in the picture.”

### 3. Appreciating Care

“Caregivers are a respected, valued profession. Caroline makes decisions about her future, and Maggie gets the assistance she needs (the way she wants it).”

### 4. Neighbour’s Keeper

“Ellen is finding work, and ways to make life a little better, for her, her son Andy, her neighbour Janet.”



## 1. Caring from a Distance

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“Yeah, don’t worry, Dad’s doing good”, Mike told his sister, and he heard her exhale in relief.

“How about you Mike? What about you?”

“I’m fine Amy, I’m just focusing on Dad right now.”

“You don’t sound great, are you sleeping? Make sure you’re getting enough sleep.”

“Yeah... enough. Listen, I’m going to go check in with Mom, I’ll talk to you tomorrow okay?”

They spoke for another couple of minutes, and then Amy hung up and Mike sighed. What about Mike. On the phone to his sister, he wasn’t going to go into a long-winded speech about “How Mike was doing”. Even if some part of him wanted to.

How was he doing? Well for starters, Mike would be doing a lot better, if Mike wasn’t doing everything. Then Mike realized he hadn’t even bothered to ask his sister how she was doing. And that made him twinge a bit, because he knew she probably wasn’t doing so great either. It’s not like she wasn’t around on purpose. The Philippines wasn’t exactly a short flight from here. Amy had always been closer to their parents, but now, as fate was ironically having it, he was the only one who was actually close.

His parents had been so proud of her when Amy (the baby and the favourite) went back to the Philippines, accepting a liaison position with a Canadian social justice group working out of Manilla. Amy was now getting the chance to get to know all the relatives Mike’s parents had left behind when they emigrated to Canada. Mike didn’t really remember those relatives. He’d only been 5 when they moved and really only grew up knowing his aunt, his mom’s sister who’d come over with them, but it was great to see how quickly their family there had embraced Amy.

Mike knew Amy felt bad that he was doing the heavy-lifting back here, and she was trying to make up for it by staying as involved with Dad’s situation as she could. She wasn’t able to be there when he had his stroke, but she was doing her best to stay on top of how he was doing now. Mike knew that Amy was watching and ready to come back if there was a sign that Dad was getting worse.

When she moved to Manilla, her company had helped her find a place to stay in a neighbourhood a lot of Canadian expats lived in. She had reliable web and voicephone connections. As a going away present, their parents had given her one of the newest weTalks, complete with violet-ray. And they’d bought another one for their condo.

What that meant now is that when Amy called, the weTalk could be moved around their parents’ place. So if their dad was having a bad day, he didn’t have to come to the computer to see Amy. He could just have their Homebot bring him the weTalk, and he could see and talk to Amy on its portable screen, and Amy could see and talk to him.

More than that, Mike and Amy were hooked into the same HealthWatch system. With their verified IdentKeys, they were listed as trusted family members on their dad's HealthRecord account. Which meant that Amy could log in and see when Dad's appointments were scheduled.

That still left Mike taking his Dad to all the appointments himself of course. And, yeah, he was starting to feel the strain. But at least Amy would know to call if there something significant in their dad's schedule. Juggling work and helping out with Dad (what Mike had started referring to as his "second job") were more than enough for him to handle. Mike didn't really feel like picking up the phone at the end of the day to update Amy, even though he didn't mind when she called, when she already knowing roughly what had happened that day.

Even the juggling of work wasn't going so bad. He was really glad he'd opted for the ElderCare package when he'd selected his optional FamilyCare benefits at work. Lots of people had gone with KidCare, but Mike didn't have kids (and at 45 he figured he probably wasn't going to), and he'd known his parents would probably need more of his help soon.

His company offered a competitive package. Granted, they had to be competitive. People with Mike's skills were scarce and in high demand: the labour shortage in knowledge workers was definitely in Mike's favour. The benefits packages seemed to be getting progressively better the longer Mike had been in his field.

Mike had just returned home from taking his dad to see his GP -- again -- and he felt wiped. Catching his reflection in the hall mirror, he stopped. Man, he wasn't looking like he was doing too good. Dark circles under his eyes, and while the whites of his eyes weren't quite bloodshot, but they weren't quite clear either. Ugh. He looked like he felt. Great.

It was probably time to tap into some of those benefits again. When Mike had first let work know about his dad, his ElderCare case manager had been in touch about some of the options available to him. There was a subsidy for remote access technology and Mike had used it to buy a weTalk as well, making it easier for him to see how Dad was doing on days when he wasn't actually at his parent's home. The case manager had also let him know about the Flextime program. So far Mike had only opted in for a more flexible working day, with more time offsite, but his dad had some regular therapy appointments these days, and Mike figured he'd probably need to make the shift to actually dropping a few hours from his work week.

He knew he was lucky that he could. When he was a kid, his aunt had cancer, and he still remembered his mom trying to find ways to help her, while keeping up with her regular job. But since caregivers had become a protected group in the provincial Rights & Responsibilities Code, there was a lot more pressure on employers to be flexible, and more understanding. Big companies could try and be a stickler for a particular work arrangement these days, but you were pretty much guaranteed to get e-mob attention and unfavourable publicity. The numbers just supported it: the "lump in the snake" was true, Mike really did feel like everyone he knew, or their spouse, was pitching in on care for one or both parents.

Mike was feeling grateful for that caregiver protection these days. It was a small comfort knowing that if he needed to take a few hours off so he could take his dad in to see his GP, then he could. Small, but pretty important.

Taking another look in the mirror, and pulling down a bit at the skin under his eyes, Mike decided to take Amy's advice and get some sleep. His job was secure, and they knew this would go on for a while. He might as well take his office up on their flexibility. He sat down at his computer, logged in to his work account, and sent his ElderCare case manager a note about moving to the reduced Flextime option. Dad was doing better, they were over the hump, but Mike knew that his parents were going to continue to need his help. If he was going to be any use to them, and to his work, then it was time to catch up on a bit of sleep.

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## 2. Designed for Living

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It was called “planned design”. Lots more buildings were being constructed that way. Luis knew more about it than most people -- probably half the construction sites he worked at were these kinds of buildings. Part of the whole Ergo Shift, or “Third Wave Eco”. Whatever you wanted to call it (some papers had labeled it “Post Carbon”). All green roofs and human-scale.

The new buildings really stood out. First Leadership in Energy and Environmental Design (LEED) had been everywhere, and now everywhere was focused on high Human Ergonomic Environmental Design (HEED) ratings. Luis could see the changes even from when he was a kid, and he was only in his late 30s now.

Well, see the changes ‘from’ and see the changes ‘to’. Like, say, his old high school. When Luis went to his 10 year reunion (he’d fudged it a little, since he hadn’t actually graduated), the ramps they’d been working on when he was a student were throughout the school (maybe even looking a little old). Now they were installing braille signs, painting the walls in contrasting light and dark colours to help visually-impaired people navigate the building, putting in railings, overall making the building “Accessibility for All” compliant. Some of the changes were obviously retrofitted, made more obvious by the not-so-subtle sponsorships embossed here and there (he didn’t think the school had energy-efficient windows when he was a student, and he was definitely sure they hadn’t had “Amitrust Bank” etched in the corners).

But places like Creek Springs were really the model for what HEED was about. The design just looked seamless. It was like walking into a prototype, not just a ramp added to the side of a building. Creek Springs had one of the highest HEED ratings in the city. Luis knew that because there was a sign about every four metres, plus one of those darned recordings if you stood too close to a billboard: “Did you know that Creek Springs and MacVale Inc have partnered to make this facility...”. Luis practically had it memorized -- they’d put one in the elevator.

Luis spent a lot of time at Creek Springs. Coming by to help with his mom every Monday and Thursday, plus Fridays or Saturdays when he could manage it. He had to admit that it was a beautiful building, even if it had taken him a while to get used to the idea that his mom lived there now, and not in the home he’d grown up in.

A few years ago it had started to become obvious that it wasn’t a good idea for his mom to live by herself. She’d had diabetes for a long time, but it was getting more complicated, and her mobility was starting to decline. It was just too hard for her to be on her own for most of the day, even with her family dropping by many evenings.

When it became apparent she’d need assisted care, her seniors’ services case manager had put them on the needs-based waiting list for Creek Springs.

Though Creek Springs wasn't actually where they'd first tried to place his mom. They'd been trying to get her into extended community support services. She'd had excellent home care when she broke her hip, but that stopped once her injury had healed.

The problem was that, when means-tested -- and everyone was means-tested now, since the government introduced it in 2020, in an effort to deal with rising hospital costs -- the Silva family made just too much money to qualify for subsidized home care. Even though Luis's mom had never had much money, and she was on limited social assistance and her savings now.

Luis thought it was interesting that the province felt that his family made too much money to qualify for public care, while they clearly made too little money to afford private care. Everyone in his family had worked hard their whole lives, but they were still caught in this limbo when they were qualifying for services. He had friends from his construction jobs who shared stories about being stuck in similar grey areas. They worked, but not enough. Or for not enough money. But the irregular nature of Luis's work was in his family's favour this time -- allowing his family to sidestep his mom into a long-term care placement with Creek Springs.

Creek Springs was a small seniors' long-term care home that actually wasn't located too far from where Luis had grown up. It was strongly tied to the local community, and the neighbourhood it was a part of. The condition of placement there was that the family had to formally commit to volunteering some time to keeping the centre going.

His mom was eligible for Creek Springs because Luis wasn't working very much these days, and could do a Monday, Thursday, Friday/Saturday plan (the specific days were flexible). The monthly rate was already adjusted based on your ability to pay, and it was even further reduced if you could come and provide some of the care directly (changing bedding; leading social activities; helping with simple physio). So long as someone in the family, like Luis or his wife, could be there for 6 hours a day, 3 days a week, and as long as the senior was on social assistance, you could apply for an opening.

Once your family member was admitted, you came for an initial orientation and then a few weeks of assisting a more senior volunteer. After that Creek Springs would fit you in where they needed help, based on your skills (Luis's construction background meant he mostly spent his time on small fix-it jobs around the centre) and availability.

There were five HEED centres like Creek Springs in or near Luis's city. Three of them had gone up within the last 10 years. Luis had even worked on a couple (though he hadn't known at the time that his mom would be staying in one of them). The first had been a pilot project, and it seemed to take forever before they broke ground on it. The communities had rallied around it though. The appetite for this kind of development was obvious: once they announced the planned location, it turned out to be the opposite of NIMBY protests, with people from the neighbourhood actually turning out to rally around the development. A number of local action groups had put up collaborative "take action" plans and WikiWorkshops on GatherRound. The rest of the centres had gone up really quickly after that.

Creek Springs was a lot more than a seniors' centre. It had integrated itself really well with the community. The space was welcoming and had attracted a lot of attention. Creek Springs

bolstered their budget by having a number of tenants who rented out the communal spaces a few days a week. Even Luis's family used them -- while he was at the centres on Thursdays, so was his daughter, going to her karate class.

Even if the talking billboards and the sponsorship name-drops could get a little annoying, Luis thought they'd done a good job on the centre. The building was bright, and open, and there was a lot of greenery around (not even counting the green roof which it, of course, had). His mom was happy there, she'd already made a lot of friends, and the arrangement was working out well for his family. It was like they'd managed to make a place you'd have to be, into a place you'd want to be.

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### 3. Appreciating Care

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Some days Maggie felt great. She really looked forward to seeing Caroline, and didn't mind that during every visit Caroline seemed to ask the same few questions. What had she had for dinner last night? How was it going today? Better or worse than last week? Or the same? Other days Maggie didn't feel so great at all, and she didn't like answering questions (never had), but she still preferred that it was Caroline doing the asking.

Maggie knew why Caroline had to ask those questions. It was all part of why Caroline came to visit her in the first place. She was a student at the college. Maggie didn't quite remember the name of her program, but she thought Caroline had called it something like "Home Support".

Caroline had started dropping by Maggie's place last spring. Maggie had a health coach she saw regularly at the community hub. The hub was a bit of a drive from Maggie's place, but her place was a farmhouse and a bit of a drive from most places. Maggie'd admit that since the hub had gone in it had saved her a lot of time, and Maggie generally liked things that saved her time. Most of the services she used to drive into the city for were now there, like her health coach (HC) and her dentist.

Plus the town had added a bunch of other services to the same building. It was connected to the grocery store, the pharmacy, a daycare centre, the internet interaction cafe, and even a couple of health and wellness studios. Recently there'd been talk of adding an exergame complex. There was one going in to the community hub the next town over, and Maggie's hub was hoping to coordinate construction with them, cutting down a bit on the installation costs. Maggie had read about it when browsing the hub's notices and services in their virtual site.

It was her health coach who suggested to Maggie that it would be good to have someone like Caroline drop by. The health coach would make all the arrangements, Maggie just had to let her know what day would be good. Maggie wasn't thrilled about the idea -- she didn't much like visitors -- but the health coach had insisted. They'd made a sort of deal. Maggie wouldn't have to come into the hub as often (to keep up her supportive assistance, she had an appointment there twice a month), but she agreed to let someone from the college come by once a week instead.

The first two kids from the college (they were in their 20s, but they seemed so young to Maggie) hadn't worked out. One was a young man who Maggie felt was not very attentive, plus he looked a lot like a brother she didn't care for. They'd reassigned him. The next was a really friendly girl who was just far too chatty and bubbly for Maggie's tastes.

When Maggie was in seeing her HC again, she let her know that it just wasn't working and that if Maggie was going to have someone coming to her house, she wanted someone better suited to her. The chatty bubbly girl, for instance, just got on her nerves. Her HC suggested they give it one more try. And that one more try was Caroline.

Caroline had studied Maggie's case information before her first visit. She knew that she was in her late 70s, and that she was in good health, except that she was beginning to show symptoms of

depression and anxiety. That was what had prompted her HC to recommend Maggie to the college's Home Support Care Services program.

Maggie was fiercely independent, and wouldn't like the idea of living anywhere but her own house. She had some complications, but for the most part she did fine on her own. She just needed someone to check in and make sure that her mental health problems didn't overwhelm her, and help her out on the weeks when they did.

Maggie wasn't sure about Caroline when they first met. But she was efficient and Maggie liked that. She was also all-business the first few times she came by, and Maggie liked that as well. Maggie didn't get on well with many people, particularly her family. But she found no-nonsense people easier to be around, so after a few wary weeks, she and Caroline were now getting on just fine -- better than fine even. Over time, Maggie had grown to like Caroline and even look forward to her visits. Maggie had a couple of cats, and they seemed to enjoy Caroline's visits as well (they'd gotten familiar enough with Caroline to start following her around for treats whenever she went into the kitchen).

And Caroline was enjoying spending time with Maggie. She'd decided on a caregiving profession while she was still in high school. One of the job shadowing options in her last year was with a health coach working in a community hub. Caroline had enjoyed working with the HC, but it was the community caregivers working out of the HC's office who really intrigued her. Caroline wasn't a people person in a general sense, but one-on-one she found most people were really interesting, and she enjoyed getting to know them. She knew that a lot of the people the community caregivers visited had degrees of clinical depression or were housebound, and Caroline felt like she understood that. She'd gone through a rough time with depression herself when she was a teenager, and she liked the idea of being able to help other people with similar struggles.

The colleges were really encouraging career choices like Caroline's these days. There had been a big shift in focus towards community-building careers. "Compassionate Caring Communities" were talked about everywhere. The economy had been stagnant for a number of years now, and Ontario was somewhere around the middle of the provincial pack as an increasingly have-not province.

People had responded by focusing on stronger communities. It seemed less possible now to pour more money into social services, though everyone had grown up thinking of them as fundamental rights they deserved access to. The province clearly didn't have the money to try and buy a better system. But the government had worked hard to revitalize choosing caregiving professions (starting with that "Compassionate Caring Communities" campaign), helping to shift them away from being unvalued work, towards being desirable careers.

Caroline's own mom had worked at a daycare, and Caroline remembered that while her mom had loved what she did, it wasn't the sort of job that other people were interested in. That had all changed as you started to hear more about caring communities. First one college offered an "advanced and integrated" degree in community care, then another. There was talk of Canada becoming a "leader in caring". Then graduates started being recruited to jobs abroad. Then

there was concern over the “Caring Drain”. Most recently, about four years ago, just before Caroline enrolled in college, the government set up a program which subsidized your tuition if you enrolled in a caregiving professional program. The only contingency was that you had to commit to work in your community for seven years after graduation. Which was less of a caveat and more of an incentive -- most students Caroline knew were just looking forward to the job security.

Caroline was one of the first batch of students who were eligible for the program, and so far, she thought, it was working out great. She loved her studies, and even more she was loving the job as she started to spend more and more time onsite, getting to know clients like Maggie. She knew it maybe wasn't the easiest career, but that was where the satisfaction came from.

The program made her feel valued and respected. Saying you were a caregiver had weight. The pay may not have changed much, but the recognition from your community had gone way up. Unlike her mom, who never got asked about her job, Caroline was asked about hers all the time. Her little cousin had even asked her if she would come and speak to her class on career day. Caroline had laughed when he'd said it, then realized he was serious. Her presentation was scheduled for a week Wednesday.

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## 4. Neighbour's Keeper

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Ellen hoped Janet knew how much Janet's help meant to her. She was pretty sure she did. After all, she and Janet had been neighbours and friends for more than 10 years.

It was only last year that the "Good Neighbours Bill" had passed though, and it was already making a big difference in all three of their lives, for Ellen, Janet, and Ellen's son Andy.

Andy had been born with severe cerebral palsy. It had been a tough go for Ellen even back when she and Andy's dad were together. Since Andy's dad had left though, Ellen had found it almost totally unmanageable. Not totally, but almost.

Ellen had early on used her direct payment allocation to get Andy an augmented communication device, a Gamma Talker, that he used at home and at school. She could also have used the money towards counseling or transportation or even some minor fixes to the apartment, but Ellen thought first things first -- what was most important was that Andy could communicate as best he can. It also helped with his frustration, which indirectly helped her.

The direct payment had been set up and was managed through NetworX, though she knew the funding came from multiple ministries -- contributions to the assistive allowance came from the Ministry of Health, from Children and Youth Services, and from Community and Social Services.

The direct payment allocation had been in place for a while: the Gamma Talker was actually a bit outdated now, and there was an exchange program Ellen was going to be using soon to upgrade it. She'd have to pay a portion of the difference, but she could afford to. Or at least she could afford to since she started working through the Alternate Care Empowerment (ACE) program. Also run by NetworX, ACE kept a list of workplaces that offered part-time work to people like Ellen (up to 20hrs/week) at flexible hours.

ACE was a big part of Ellen's life right now, but as Andy got older, it would more directly become a big part of his. Through ACE he would have his own care worker who would manage Andy's file as he grew up, connecting him and Ellen to the changing services they would need over time. If it was possible for Andy to have a volunteer position in the community, the care worker would help identify those opportunities. As Ellen got older, the care worker would begin preparing with Andy for when she was gone, helping him to direct his own care, and plan for his future.

But for now ACE's services were mostly focused on Ellen. While she was working at an ACE-participating company, Ellen qualified for CPP contributions, recognizing her role as Andy's primary caregiver. His primary caregiver, but not his only one.

Janet had always been a big help to them. It was hard that even with the help of social assistance, none of them (Janet, Ellen, or anyone in their neighbourhood really) had much

“extra” -- time or money. It had been difficult for Ellen to know that time Janet spent helping her was time taken away from Janet’s own (much-needed) paid work.

Janet never said anything, but Ellen suspected that a couple of times she’d had to ask Janet for help, Janet had cancelled shifts so she could be there. Since the Good Neighbours Bill (GNB) though, the arrangement had started to work well for both Ellen and Janet. GNB made it easier for anyone to help with respite care. If you were verified as a caregiver, and pitched in a few hours a week to help to someone in your community, GNB meant you were eligible for a small tax credit.

It was nothing huge, but it was enough to compensate Janet for that bit extra she was doing that was making that big difference to Ellen, and to Andy. For Janet to qualify, Ellen had to verify that she wanted to use a portion of her direct payment to help pay for Janet’s time, and they were visited once a year by someone from NetworX who made sure that it was all on the up and up. There were of course ways of reporting (yourself, or as a third party) if it wasn’t on the up and up, but so far there had been very few cases where that became an issue.

Through GNB, if Janet had been providing more complicated care, or wanted to help but wasn’t as familiar with Andy’s needs as she was, NetworX would have connected her to the right programs (the training would also have counted towards her volunteer relief time). But Ellen and Janet had known each other for so long (Andy had ages ago started calling Janet “Auntie”) that Janet knew Andy’s needs almost as well as Ellen. It was good to know though that not knowing as much wouldn’t stop people from being able to help. They might be cleared only to help out in simpler cases, or for less time, but Ellen knew all too well that any amount of help you could get was invaluable.

Getting the logistics sorted out once a year was more than worth doing to Ellen. After all, Andy loved Janet, he knew Janet, and he was comfortable with Janet. Which meant that Ellen could take those few hours a week and get some errands done, or maybe just have a bit of time for herself.

Janet had wanted to be of more help years ago, but before the Good Neighbours Bill, she mostly couldn’t afford to take the time (even if that hadn’t always stopped her). The GNB credit basically worked out to another shift of work for her, and that made a difference. With GNB, Janet was actually ending up in basically the same position, maybe a little better (given the long-term stability of Ellen needing her caregiving help). And Ellen and Andy were ending up way ahead.

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