## Canada will soon allow medically assisted dying for mental illness. Has there been enough time to get it right?

With doctors divided and federal guidelines still in development, Canadians have questions about who will qualify for MAID next year – and whether it's a good idea to give the most vulnerable an easier way to die

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Psychiatrist Madeline Li worries that Canada is expanding its assisted-dying laws too quickly, without careful safeguards and enough transparent oversight to prevent mistakes.

IAN WILLMS/THE GLOBE AND MAIL

The date whispers in Julie Leblanc's mind when she is feeling most hopeless. It tugs at her thoughts when, for days, she forgets to eat, or doesn't shower. She thinks about it more than she knows she should.

On March 17, assisted dying will become legal for Canadians with a mental disorder as their sole condition, and Ms. Leblanc can apply.

She has been struggling with mental illness since she was 8 years old. At 13, she was prescribed her first trial of anti-depressants; now at 31, she has tried too many medications to count, and spent much of her life either in therapy or waiting on a list to receive it. Bounced between doctors, she has been given multiple diagnoses – depression, anxiety, post-traumatic stress disorder, borderline personality disorder.

She wavers between wanting to die and trying to live, especially for her 11-year-old son who is cared for by her parents. She tries to feel hopeful about the earnest new psychiatrist, her third in a year, who patiently listened to her at their first appointment in September. But she is tired of retelling her story. It never seems to help. She feels trapped in despair and anxiety, while carrying the deepest sorrow of all – her illness prevents her from being a good mother to her son.

She has tried taking her own life before. But she worries now about suicide being painful, or ending up in a wheelchair, which happened to someone she knows. She has researched <u>medical assistance in dying</u> online. MAID sounds peaceful, she says. And also too tempting. How can it be, she wonders, that the same system meant to keep her alive might soon help her die?

When that option arrives in March, Canada will have one of the most liberal euthanasia laws in the world, joining only a few other countries that allow assisted dying for mental illness.

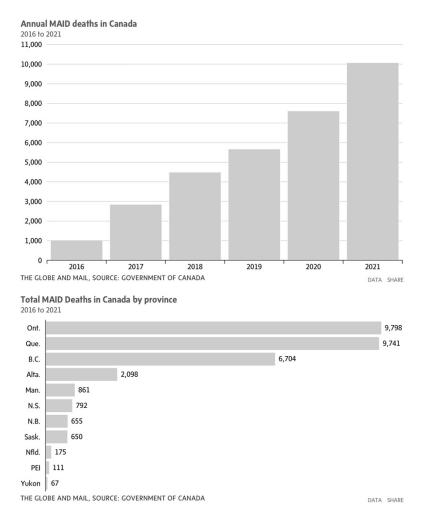
It will be the most controversial expansion of MAID since a Supreme Court ruling led the federal government to <u>legalize euthanasia in 2016</u>. At that time, MAID was only for patients with a foreseeable death, but Parliament – with Bill C-7 – removed that requirement in 2021.

The original version of the bill did not allow assisted death for patients with mental disorders as a sole condition because, the government said at the time, there were outstanding questions about how illnesses such as depression could be safely included, and what the future implications might be. The Senate disagreed, removing that exclusion before the bill passed, but with one caveat: Parliament would study the issue for two years before any of those patients could receive MAID.

With four months to go, there is still no consensus in the mental health community – and, in fact, doctors remain deeply divided. There are no finalized

national standards, no transparent review process in place to watch for mistakes, and hospitals are still figuring out how they would implement the change.

Toronto's Centre for Addiction and Mental Health (CAMH), Canada's largest psychiatric teaching hospital, has said that assisted dying shouldn't expand without more study. And the Canadian Mental Heath Association has raised serious concerns about expanding MAID without first increasing mental health care funding. In Quebec, after public consultations, a legislative committee has recommended against the province expanding MAID to mental illness at all.



Meanwhile, In Ottawa, the federal parliamentary committee reviewing the law was supposed to publish recommendations in October. Instead, after months of emotional and polarized testimony from psychiatrists and researchers, the MPs and Senators will now report back next February, just weeks before MAID automatically expands.

Expert dissension, a law without clarity, the arbitrary legislative finish line – all of this would be worrisome, even in normal times. But Bill C-7 passed before the full consequences of COVID-19 were known, before the pandemic ripped through the health care system and left it in tatters.

The law requires patients asking for MAID to be informed of possible treatment options that might alleviate their suffering. But this assumes those are readily available. Instead, wait times to see mental health clinicians have only increased.

Psychotherapy, a recommended treatment for most mental disorders, remains too expensive for many Canadians. In Toronto alone, an estimated 16,000 people are waiting for supportive housing for mental illness and addiction.

In Ontario, nearly 6,000 patients with the most severe mental disorders are on a years-long list for specialist community-based care.

The rising cost of rent and food is also taking a particular toll on people with chronic mental illness, who are often already the poorest in society – and the very candidates who will qualify for assisted dying under the new law.

Just as life is getting harder in Canada, it is getting easier to die.

For advocates, expanding MAID is about not discriminating between mental and physical health, about seeing patients as whole people capable of making their own decisions.

Critics, on the other hand, suggest that MAID will become an easy out for a broken health care system, offering death rather than hope and treatment to society's most vulnerable and marginalized citizens.

Whether Canadians have fully debated where we stand as a society on these moral and medical questions is almost immaterial at this point.

With March red-circled on the calendar, Canada is speeding toward its own unique life-or-death experiment. The country needs to make sure that expanding MAID is safe for patients.

Do we have time to get it right?



'After all is said and done, the paramount issue is: what does the patient want to do?' says Derryck Smith a member of the Canadian Psychatric Association's assisted-dying committee. Dr. Smith is among a relatively small group of psychiatrists currently involved in Canada's MAID process.

When MAID was first legalized in 2016, it came with a narrative that was comforting to many Canadians: faced with a painful, imminent death, patients – most of them in their senior years – would choose, after a conversation with their doctor, to die on their own terms, peacefully, with dignity, and surrounded by their family.

As the number of Canadians receiving MAID has steadily increased, this narrative has remained largely true. In 2021, there were 10,064 assisted deaths in Canada – an increase of 32 per cent over 2020. The average age of Canadians who received MAID last year was 76. Two-thirds have a cancer diagnosis, and nearly one fifth have a heart condition.

They tend to be wealthier Canadians – more likely, as an Ontario study found, to fall into the highest income bracket than the lowest. They have been, in other words, people of relative privilege, wanting the same control in death that they had in life.

Testifying in support of MAID's expansion last spring, Derryck Smith, a B.C. psychiatrist, shared the example of a woman in her 40s who he assessed for MAID. She was the daughter of a judge, he said, who had struggled with anorexia for years. No treatment had worked; private clinics in the United States had failed to help. She had been hospitalized and tube fed against her will. She vowed to go home and starve herself if she wasn't approved for MAID. Reluctantly, her father, interviewed by Dr. Smith, agreed to support her decision. Her condition was deemed incurable, her suffering intolerable, and she received an assisted death.

Dr. Smith, who sits on the assisted dying committee for the Canadian Psychiatric Association, and is a member of the Canadian Association of MAID Assessors and Providers, falls on the patient autonomy side of the debate. He acknowledges that the health care system is broken and underfunded. But he argues that if a person is capable of consenting, meets the legal requirements, and wants to die, it would be morally wrong to deny their right to choose. Otherwise, those patients are truly trapped: they can't get timely treatment to alleviate their suffering, and they can't choose to end that suffering themselves.

"After all is said and done," Dr. Smith said, "the paramount issue is: what does the patient want to do?"

Mona Gupta, head of the federal expert panel, told the parliamentary committee last spring that excluding MAID for people with mental illness, "suggests that, as a society, we don't believe that people with mental disorders can really ever be capable of making their own decisions for themselves."

But this ethical argument raises another: Can a person freely choose to die if they don't have an equal chance to live with dignity?

Unlike the judge's daughter, people with chronic and severe mental illness are not typically travelling out of country for top-tier private care; many of them will not even have family doctors, let alone regular contact with specialists.

Compared to the general population – and compared to the Canadians currently getting MAID – they are significantly more likely to be unemployed and homeless. Their stories will often be complicated by trauma, childhood abuse, and addiction – their symptoms compounded by financial stress and loneliness.

Rather than worrying about equal opportunities in death, says Sonu Gaind, chief psychiatrist at Humber River Hospital, society should first correct the wrongs his patients face in life.

"This is about the autonomy of the privileged at the expense of the marginalized," he says.

In the Netherlands, where euthanasia for both physical and psychiatric illness has been legal for 20 years, studies have found that patients who receive an assisted death for a mental health disorder tend be younger and poorer than those with a physical illness.

They are also significantly more likely to be women – a statistic that has raised concerns among suicide prevention experts. In the Netherlands, as in Canada, men and women receive euthanasia for physical illness in roughly equal numbers. But for psychiatric euthanasia, Dutch women outnumber men roughly two to one. Researchers point out that this pattern aligns with another statistic: although death from suicide is higher among men, women are twice as likely to attempt suicide. One of the reasons for this difference is women tend to choose less-lethal means. The concern that experts raise, then, is that state-sanctioned assisted dying – without careful safeguards – may give women, in particular, access to a more socially acceptable but lethal method of suicide.

This is why the debate is so emotional for many doctors: they fear that people will die before they have chance to recover.



With the rising cost of food and housing, and wait times for treatment increasing, mental health advocacy groups have raised concerns that assisted dying will become an option for some of the most vulnerable Canadians just as life in Canada is getting harder. IAN WILLMS/THE GLOBE AND MAIL

The current MAID law in Canada establishes two tracks of patients – those whose death is foreseeable, and a second who have "grievous and irremediable conditions" that aren't terminal and whose suffering is intolerable. In both cases, people must be 18, found capable of making a decision, and be approved by two doctors. For cases that aren't terminal, there is 90-day waiting period after approval, and one of the assessors must be a specialist in the patient's conditions.

The problem is the law calls for medical findings that are still fiercely debated in research. And even in practice, psychiatrists seeing the same patient don't always reach the same conclusions. For starters, there's no clear consensus about whether doctors can tell the difference between a patient who is making

a rational, independent request for MAID and one who wishes to die from suicide because of their mental disorder.

Defining "irremediability" is even more contentious. Unlike cancer, doctors can't rely on lab tests and brain scans to diagnose mental illness. Predicting what will happen to anindividual patient with a mental illness is even harder because the outcome of psychiatric disorders isn't reliably connected to how long – or how severely – someone is sick.

A 2016 large-scale American study, for instance, followed people with mental illness for 12 years – and found that the chances of recovery actually increased over time. Last month, a paper published in the journal Psychological Medicine reviewed the existing research on predicting outcomes for treatment-resistant depression; while computer algorithms and doctors in some smaller-scale clinical trials were better at determining outcomes, in the study that most closely replicated real-world conditions, psychiatrists got it right only about half the time. When it comes to psychiatric euthanasia, the authors concluded, "the object standard for irremediability cannot be met."

Even the expert panel reporting back to Parliament concluded that "it is difficult, if not impossible, for clinicians to make accurate predictions about the future for an individual patient." (The panel itself wasn't immune from controversy: before it could finish its report, two of the 12 members had resigned, citing ethical reasons.)

Christie Pollock, a 31-year-old university student in Vancouver offered her own story as a cautionary example in a written brief she submitted to the parliamentary committee. For more than a decade, she said, "I had lost all hope of getting better." She has been diagnosed with a long list of disorders, including borderline personality disorder, severe anxiety, depression and a panic disorder. Since she was a teenager, she's seen a dozen different therapists and tried many different medications. Nothing worked. She overdosed four times, and was hospitalized repeatedly. But then, after years of trial and error – and doctors, she said, who refused to give up on her – she found the right combination of medication and therapy.

Today, she is studying psychology and facilitates a support group; her symptoms are manageable. She has a life that she never imagined for herself. If MAID had been available, she wrote in her brief, "I might simply be a memory."

But medicine, Dr. Gupta told the parliamentary committee, is a discipline largely guided by probabilities. "We can never remove all certainty," she said. She pointed out that doctors are already assessing health issues, such as chronic pain, with unclear outcomes. In the end, the expert panel found that it wasn't possible to come up with fixed rules about how many and what kinds of treatments a patient should get before receiving MAID. Instead, the panel recommended that a doctor establish incurability by assessing the treatment history, and length and severity of the illness.

In other words, critics counter, the panel proposed that doctors study a patient's past to predict their future – the very method disputed in research. John Maher, a psychiatrist in Barrie, Ont., asked the parliamentary committee, "How many mistakes are you prepared to make?"

In October, Madeline Li, a psychiatrist at Princess Margaret Cancer Care in Toronto, appeared on Zoom before the parliamentary committee. Her tone was soft – the voice of someone used to soothing dying patients – but her message was clear. The current MAID law, she said, gives too much power to doctors to make their own value judgments about what makes life worth living. The legislation needed more clarity to guide assessments. Cases needed to be more carefully reviewed after patients died to make sure the process was safe.

At the hearings, MAID providers have insisted the process is careful and rigorous, even more so for cases where death is not foreseeable. The number of people who seek MAID solely for mental illness will be small, they assured the committee, and the number approved from that group even smaller. They point to the Netherlands, for instance, where psychiatric euthanasia, though increasing steadily over the last decade, still accounts for a tiny fraction of all cases. A larger issue, they say, will be offering equal access across the country, and ensuring there are enough psychiatrists to provide timely assessments for patients who want them.



Dr. Li has administered MAID before and shaped the protocols for other practitioners in Toronto's University Health Network. IAN WILLMS/THE GLOBE AND MAIL

But among the many experts who have lined up to express their objections to the direction and pace of Canada's euthanasia laws, Dr. Li's deserves particular attention. She led the creation of MAID protocols at the University Health Network, a group of Toronto-area hospitals that together form the largest health research group in the country. At the national association for MAID providers, she is the scientific lead currently developing the government-funded assisted-dying curriculum for doctors. She has administered assisted deaths directly to patients, and provided oversight to hundreds of cases as the MAID program lead at the UHN.

All that experience, she said in an interview, has made her personally opposed to expanding MAID for patients without a foreseeable death, especially those with mental illness. The debate among doctors has become too ideological, she said, and the current system doesn't have enough safeguards to prevent unconscious bias from factoring into decisions.

Can doctors – a mostly healthy, privileged group of people living in a society that routinely stigmatizes people with disabilities – objectively judge what makes life worth living? Dr. Li says she once watched a doctor use an actuarial chart to calculate that an older woman seeking MAID after a fall had, on average, three years left to live; he approved her for MAID, over the objections of three other physicians. "What if it had been six?" she asked. "How many years is enough?"

Dr. Li worries that since many psychiatrists won't participate in MAID, there will be "an echo chamber of a few assessors who will all practice in the same way," leaning hard toward patient autonomy. Already, she argues, MAID assessments are too often focused on whether a patient is eligible for an assisted death, rather than exploring why a patient wants to die in the first place.

The federal expert panel recommended that decisions should be made on a case-by-case basis, with the doctor and patient reaching a shared understanding. But while the law requires that patients must give "serious consideration" to clinically recommended treatments to relieve their suffering, they can refuse those treatments if they don't deem them "acceptable."

For instance, Dr. Li described the case of patient in his 30s, who asked for an assisted death, even though multiple doctors said his cancer was curable. Two assessors approved him for MAID. Faced with his adamant refusal to get treatment, and his progressing condition, Dr. Li said she helped him die "against her better judgment." If MAID didn't exist as an option, she believes he would have gotten treatment, and still be alive.

Since finding the right treatment for a complex mental disorder takes time, and conditions such as depression often make patients pessimistic about the future, clinicians have raised concerns about being pressured to approve MAID, even when

they believe a patient might reasonably recover. There is also no limit on how many times a person can be assessed, raising worries that patients will "shop around" until they get approved.

Of course, a bigger issue than patients refusing treatment is what happens when the treatment that might help them recover isn't available. The current law requires that a person seeking MAID be offered consultations with professionals who provide recommended treatments, and the expert panel specifically suggested that they should include social services, such as housing. But often a doctor can't easily find those services, or a patient can't afford them. Already there have been controversial cases of Canadians requesting MAID, at least in part, because they couldn't get enough home care or access proper housing.

In a telling exchange at the parliamentary committee, Dr. Maher argued that a system that cannot provide care should not offer death as an alternative. For instance, he said some patients will have to wait five years to get the kind of specialty care he offers. "Telling my patients that you will make it easier for them to die has enraged me," he told the committee. "They will die because psychiatrists will now have legal permission to give up."

Testifying on the same day, Ellen Wiebe, a MAID provider in B.C., said that if a patient told her that they weren't willing to suffer five years while waiting for treatment, "then I would say that was irremediable."



People with chronic and severe mental illness are more likely to be poor and homeless than the genera population. In Canada, there have already been examples of people seeking an assisted death, in part because of a lack of social services such as affordable housing.

IAN WILMS/THE CLOBE AND MAIL

For lessons, Canada can look to the few countries with a longer history of psychiatric euthanasia. In both Belgium and the Netherlands, front-line clinicians have warned other countries to proceed carefully.

In Belgium, for instance, some psychiatrists have argued for a two-part system – one that assesses patients for assisted dying, a second that independently investigates treatments to help them recover.

In the Netherlands, although the law does not specify standards of care, the Dutch Psychiatric Association has created clear guidelines, which, in particular, require two independent psychiatrists to assess a patient. (In Canada, the law currently requires only one specialist.) The second opinion is meant to explore possible treatment options, explains Sisco Van Veen, a psychiatrist at Amsterdam University Medical Center who assesses people for euthanasia, and also researches the issue.

Unlike the current law in Canada, which makes the acceptability of treatment ultimately the patient's decision, Dr. Van Veen says that if psychiatrists deem "the treatment refusal to be unreasonable they will deny the euthanasia request." In cases where psychiatrists disagree, a doctor who goes ahead with an assisted death must justify that decision in writing. Expert regional committees review every case, and publish detailed findings online.

The cases of psychiatric euthanasia in the Netherlands, while still relatively rare, began rising in 2012 with the opening of an end-of-life clinic. Psychiatrists there now handle the vast majority of cases. For about 90 per cent of patients who apply, an assisted death does not happen – the majority are deemed ineligible, Dr. Van Veen said, but a significant number also change their minds or get adequate treatment. Of course, proportionate to Canada, the Netherlands spends significantly more on mental health care.

Another issue to consider is how to make the assessments as thorough as possible. In the Netherlands, the clinic requires patients to sign a waiver making all relevant medical records available, and allowing communication with the doctors who have treated them, says Dr. Van Veen. Family caregivers are also usually interviewed, except in cases of abuse. Doctors can deny a euthanasia request if relatives are not involved.

The Dutch approach isn't perfect, and there are still controversial cases. But it shows how, with careful steps, a euthanasia system can also save some patients.

In 2020, Dr. Van Veen co-authored a paper about a Dutch patient who, for eight years, had been hearing childhood songs playing daily on repeat in his

head. Among his collection of diagnoses, he had a history of psychotic episodes from schizophrenia.

Medication to quiet the songs had not worked and, at 36, he finally asked for an assisted death at the end-of-life clinic. Doctors there assessed him over the course of a year, and then sent him to an independent psychiatrist – a specialist in schizophrenia – for the required second opinion. That doctor, after a careful clinical investigation, proposed a different cause for the songs, and prescribed a new drug, along with psychotherapy.

Within weeks, the patient was in full remission. At the time his case written up, the patient had withdrawn his request for euthanasia.

"It was a close call," says Dr. Van Veen.

You can draw one of two conclusions from this cautionary tale, he said. Either psychiatric euthanasia cannot account for uncertainty, and thus should never happen. Or a system with clear safeguards works.



The final decision

Konia Trouton, a physician and MAID provider in Victoria, <u>reflects</u> on the solemn dance she performs with her patients – who are always in the lead.

The final decision: When I provide assisted dying, it is about grace and choice – and that must remain the case

https://www.theglobeandmail.com/opinion/article-the-final-decision-when-i-provide-assisted-dying-it-is-about-grace-and/

Jane Hunter, a retired businesswoman who lives near Lake Simcoe, believes accessing MAID is her legal and moral right. She says she plans to be first in line come March. Her form is already filled out.

Long years of failed treatment and pill cocktails have worn the 73-year-old down. She is angry at doctors, who she feels dismissed her symptoms and ignored her trauma history. Now diagnosed with complex PTSD, she says she is tired of the side effects of the medication, of living alone with constant sadness and terrible memories. Divorced with no kids, most of the people in her life have walked away. In April, she says she attempted suicide twice. Now she is holding out, she says, for a dignified death with MAID.

"I am in constant pain, and I don't want to live. Why would anyone question that?" There are things she will miss: the warmth of the sun, her garden in the

summer. Death isn't a joyful choice, but to stop her suffering she is adamant: it is her choice to make.

Perhaps society, by putting into place Bill C-7, shows it agrees. But laws and standards should still protect the complicated patients, the ones who have no advocates and few advantages, whose case history is complex, who might not want to die if they had a house and a job, and a life with meaning. And a system can't just promise to be safe; it must also prove it – with diligent, and transparent oversight.

Canada needs to find a "muddy middle," says Dr. Li. But that's a complicated place, one the country seems unlikely to find by March.

Certainly, experts argue, doctors should know what recommendations will be accepted, what specific standards will guide them, what training they can get – ideally well before the first patient arrives in their office next year.

"It would be helpful to have more time to have these discussions," says Tarek Rajji, chief of the Adult Neurodevelopment and Geriatric Psychiatry Division at CAMH, who co-signed a committee brief in May calling for a delay. He said that doctors need more clarity on how to make assessments so that decisions are consistent, and complicating factors such as a patient's social context are properly considered. Most significantly, he said, there has not been enough consultation with actual patients and their families – the Canadians who will ultimately bear the burden of an assisted death. But, since a postponement seems unlikely, at this point, CAMH is currently working on a hospital-wide policy to be ready for March.

Expanding MAID isn't only a medical debate, ethicists point out – it has cultural consequences that may seep, over time, into how we measure intolerable suffering, what investments we prioritize in health care, the value we place on certain lives, our definition of a good death. The debate won't end with mental illness – as part of its mandate, the parliamentary committee is also hearing testimony on whether to give mature minors access to MAID, and how to allow advanced requests, particularly for Canadians with dementia.

"For a society to be able to look itself in the mirror in 100 years," cautions Dr. Van Veen, from Amsterdam, "we really have to be careful."

Meanwhile, in Ottawa, Ms. Leblanc wavers back and forth on whether to apply, depending on the day. Her new psychiatrist has adjusted her medication. She's

on a waiting list for a group therapy program. But winter is coming, and that's the hardest season. "I am trying to find hope," she says. "But it will be dangerous to have MAID in my pocket."

Sometimes, she feels betrayed, as if society is giving up on her. Another part of her feels thankful. "Finally they are paying attention," she says. "It validates that my pain is real."

## https://www.theqlobeandmail.com/canada/article-maid-canada-mental-health-law/

Once again, we tackle complex, subtle issues and come up short, defaulting into "bedrock" pronouncements settling upon some supposed moral truism that can be dressed-up and sold as defensible. There are a multitude of perspectives—as many as the people involved, maybe more given the divisions within people themselves—to be reckoned with in MAiD matters. Inevitably, it becomes about the "professionals" involved as much (or more) than the afflicted. This ultimately is a failure taken too far.

If there is a sorrier medical profession than psychiatry, I haven't come across it. Aside from what can be obtained from a few accomplished authorities at prestigious teaching clinics, the psychiatric services available to the general public are abysmal and pathetic. (I am not without sympathy for the many well-intentioned practitioners—including GP's forced to act as psychiatrists—put in impossible situations daily.) In the lengthening list of "helping professionals" I hope I never fall into the hands of—social workers, addictions counsellors, cops—psychiatrists might be at the top. Psychologists and counsellors float around on the list too. Doctors of all kinds worry me, but like everyone else, I will in all likelihood, unless a meteorite lands on me, have to eventually submit into the care of some of them. And like many, I may well end up pleasantly surprised and grateful.

My colleague and neighbor here, a good man well-travelled and afflicted by the vicissitudes of modern life, is Algerian, more precisely Berber but very "French" in taste, style, and culture. As a young farm boy fresh at university, I eagerly studied Philosophy in my first year. Here I encountered an existentialist—he insisted that he was rather an absurdist—French "Pieds Noir" Algerian who was, radically, an intelligible philosopher:



"The only serious question in life is whether to kill yourself or not."

- Albert Camus

Cheery stuff. Having come through the travails and horrors of WWII and then the polarizing Algerian War—he took a stance no one liked—M. Camus, brilliant writer with a gift for putting the profound (perhaps) prosaicly, knew whereof he spoke. Coming out of those times prepared him (and others) to frame the terms of the future where discordant things keep coming home to roost as we settle steadily into dystopian times. Ironically, the decision to live or die was ultimately made for Albert: passenger in a fast car driven by a friend coming home from a New Year's family holiday, M. Camus died instantly when the car crashed on a long straight stretch of road, raising suspicions the KGB—socialist Camus opposed the USSR for Stalin's totalitarianism—had assassinated him. But as other lives drag on, more keep having to answer Albert's question. TJB