When all else fails for terminal patients, there is another option

THE RIGHT TO TRY

DEBORAH SIMS

How far would you go if you were told that you had an incurable cancer and just 12 months to live?

I went 12,000 miles to save my life. After being declared terminally ill two years ago, I moved from Melbourne to the UK to enter a clinical trial of an experimental drug at Barts Hospital in London. There were only 75 of us on this trial worldwide. Three months later I was in complete remission. Six months ago I was told I had no detectable cancer.

But fewer than 3 per cent of terminally ill patients can access such trials. And drug companies are wary of opening compassionate access schemes because adverse effects outside of trials could affect their drug’s approval.

This means dying patients have to wait for phase 1, 2 and 3 clinical trials, where the experimental treatment is randomised against the existing treatment in an antiquated system to get drugs to market. My drug for chronic lymphocytic leukaemia has taken 30 years to reach that stage.

My drug has since received Therapeutic Goods Administration approval — but it is still not available on pharmacy shelves.

In a cruel case of irony, the drug was created in Melbourne. But I am still forced to make the long, expensive journey to the UK every three months to give a blood test and return with my daily supply.

All this is so I can receive an Australian-created drug that is available to me in the UK, but not here. It’s also been approved in the US, but not here.

This cruel absurdity puts lifesaving drugs out of reach and must be dealt with.

In Victoria, where the government is pushing ahead with assisted-suicide legislation giving terminally ill patients the right to end their own lives, the question needs to be asked: why can’t we introduce “right-to-try” legislation, which would also give them the right to try and save their life?

Right to Try laws are commonplace in the US.

They were created to enable terminally ill patients to try experimental therapies that have completed phase 1 testing but not yet been approved by the Food and Drug Administration.

Right to Try expands access to potentially lifesaving treatments years before patients would
normally be able to access them. No one can guarantee that a particular treatment will be effective, but these laws return choice and control over treatment options to where it is most effective: with patients and their doctors.

I was only 40 years old, with three young children (pictured), and I was prepared to do whatever it took to be here for them. Wouldn’t you want the option to try anything to save your life?

Right to Try laws are designed to help the other 97 per cent of patients who cannot enter clinical trials. It has been signed into law in 37 states in the US — helping to eliminate the legal barriers to access. The legislation has its roots in the HIV epidemic, as realised in the movie Dallas Buyers Club, where people with the virus sought access to experimental drugs through sometimes illicit means.

But the current state of legislation began in 2014, thanks to the work of the Goldwater Institute, a Phoenix-based libertarian think-tank that objected to what it saw as unnecessary government interference between patients, their doctors, and pharmaceutical companies.

Right to Try has been endorsed by the Trump administration with the support of Vice-President Mike Pence, which has given the movement added momentum.

Some physicians, ethicists, and regulatory officials say the laws could harm more patients than they help — but who could argue with any one patient’s quest to save his or her life?

If a doctor believes an investigational drug is your best hope, they can then initiate contact with that drug manufacturer’s compassionate-use program to discuss options for access.

Few diseases exemplify the need for Right to Try legislation more than motor neurone disease — the average MND patient survives less than 2½ years post-diagnosis.

There is only one approved medication and it extends life by only a couple of months. Patients die before clinical trials can go through their phases.

Right to Try offers hope to people with no other options.

By allowing dying patients to conduct their own trials, under doctor supervision, we will discover uses for drugs under conditions scientists had not expected.

There are passionate views on both sides of the assisted-suicide debate. Surely everyone can agree that, first and foremost, we should know whether we have done all we can to save a life.

Had Right to Try legislation existed in Victoria, ironically the birthplace of my drug, Venclexta, I and many other patients would have been able to access it outside of a clinical trial.

I am lucky I managed to get it; others are no longer here to share their stories.

DEBORAH SIMS IS AN EXECUTIVE AT THE INSTITUTE OF PUBLIC AFFAIRS
Bank tax ‘already hurting economy’

ADAM LANGENBERG

THE State Government’s bank tax has damaged South Australia’s reputation even before it has passed, a think tank says.

An Institute of Public Affairs report found the Government had done little to assure investors the new tax was “anything but an opportunistic grab for money off the back of a Commonwealth policy initiative that it had no part in designing.”

Treasurer Tom Koutsantonis dismissed the IPA as an “advocacy group for the Liberal Party” as debate began in the Lower House on the State Opposition’s motion to strike out the bank tax, which would raise $370 million over four years.

IPA Senior Fellow Chris Berg pointed to Bank SA shelving a plan to create 150 jobs as a sign of lost confidence in the state and said a London-based fund manager had moved to reduce their investment exposure in SA as a result of the tax.

“Damage has already been done. If the Parliament rejects the bank levy, it ought to immediately work to ensure investors that South Australia is not a risky place to invest in,” Dr Berg said.

That is enough for it to be defeated in the Lower House, but the Opposition, NXT MP John Darley and Australian Conservatives MPs Rob Brookshires and Dennis Hood have vowed to block the “toxic” levy in the Upper House.

Mr Koutsantonis repeated his claim that the Government legislation was robust enough no South Australian would pay as a result of the tax.

“The levy is a tax on five east coast banks that will fund thousands of local South Australian businesses,” he said.

HAVE YOUR SAY: DO YOU SUPPORT THE BANK TAX?

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CUT RED TAPE TO LAUNCH FIVE-STEP RECOVERY PLAN

We’re wallowing in economic myths instead of rediscovering the path to growth

DANIEL WILD

A popular myth is that Australia survived the 2007-08 global financial crisis because our major banks didn’t collapse and a technical recession was never called, but closer inspection reveals we didn’t survive the GFC. Indeed, the prospects for many workers and businesses have never been worse.

Nonetheless, we should be optimistic about our future. Here are five steps the government should follow to turn the economy around and restore prosperity.

Step one is to stop living in denial. The economy is in bad shape. Private sector real wages went backwards by 0.3 per cent over the past year. Business investment is expected to reach a record low 9 per cent of GDP in just three years. And the unemployment rate is closer to 15 per cent when those marginally attached to the labour force are counted, as Adam Creighton showed on this page on May 22.

Meanwhile, annual income growth has been 65 per cent slower since the GFC than in the years between the Keating recession and the GFC. And to top it off, government debt will reach $725 billion by 2027-28. All this after 26 years of unbroken economic growth.

Step two is to understand that we do not have a deficiency in aggregate demand. We have a collapse in the capacity of the economy to generate wealth. This is why productivity growth and investment are low. When there are fewer things of value being produced, there is less income being generated.

Calls for more government intervention to support aggregate demand are wrongheaded. We have had a decade of deficits, monetary easement and public infrastructure spending. Yet, instead of productivity and growth, all we managed was more debt.

Step four is to stop listening to the usual suspects.

We were told by the Treasury, the Reserve Bank of Australia and numerous private sector economists not to worry about the end of the mining investment boom. Non-mining investment would pick up once the exchange rate depreciates and interest rates and wages drop.

Well, the exchange rate is down 25 per cent since 2011, interest rates have been at record lows since 2013, and many Australians haven’t had a pay rise in years. Yet non-mining business investment is missing. The usual suspects have long been forecasting that business investment and growth would come back. But how?

Which brings us to the last step: eliminate bad policies. There are many to choose from, from high corporate and personal income tax rates to an overbearing regu-
latory state. One area often talked about but seldom acted upon in earnest is red tape.

Most people think of it as a few pesky forms that must be filled in, or a couple of hours on the phone to the local council.

However, what most people don’t know is that it can take up to 5000 licences, approvals, and permits to set up a new mine, as was the case with the Tad’s Corner Project in central Queensland’s Galilee Basin.

Meanwhile, starting a new restaurant in NSW requires filling out 48 different forms and obtaining 72 licences.

Red tape could well be the biggest impediment to growth in Australia.

Recent IPA research found that red tape costs Australia $176bn a year in lost economic output. This makes red tape Australia’s biggest industry. The good news is that there is a lot of low-hanging fruit.

Here is where the government should start. Implement a one-in, two-out policy, meaning that for every new rule or restriction implemented, two must be repealed.

Of course it is a crude approach, but it is easy to implement and worked wonders in the Canadian province of British Columbia. Abolish the energy efficiency equipment program that mandates minimum energy efficiency levels for commercial and residential equipment and appliances, and which adds to the cost of products without making a difference to the environment.

Eliminate section 487 of the federal environmental law, which allows green groups to sabotage development without incurring the costs of their actions.

Remove domestic regulation of product safety standards and instead permit market entry of all products cleared by overseas regulators of good standing.

Domestic regulations add to compliance costs without improving safety outcomes.

There is no shortage of red tape. The government should start cutting. It will make a bigger difference than most people think.

Daniel Wild is a research fellow with the Institute of Public Affairs and previously advised on macroeconomics at the Department of the Prime Minister and Cabinet.

Stop listening to the usual suspects. They have long been forecasting that business investment and growth would come back. But how?
Abbott is only ‘helping Shorten’

Andrew Tillett

One of Tony Abbott’s former loyalists has become the latest cabinet minister to unload on the former prime minister, warning the white anting of Malcolm Turnbull only helps Opposition Leader Bill Shorten.

In the latest instalment of a campaign by ministers to pressure Mr Abbott to curtail his damaging commentary, Environment and Energy Minister Josh Frydenberg said the former prime minister must focus on delivering good government.

Mr Frydenberg, a prominent conservative and a former numbers man for Mr Abbott, stopped short of saying Mr Abbott should quit Parliament but said he had to answer “one simple question”: who gained the most by his “constant critiquing” of the government?

“Is it the party members who want to see the continuation of the Liberal government? The answer is no,” Mr Frydenberg told ABC Radio.

“Is it my parliamentary colleagues who want to see them retain their own seats and the government stay in office? The answer is no.

“Is it the Australian people, who want to see a government talk about how we’re boosting funding for education and health, infrastructure, and people with disabilities as well as protecting their national security and the answer is no.

“Or is it Bill Shorten, the alternative prime minister, and he is the one who is benefiting the most unfortunately from Tony Abbott’s constant interventions.”

Mr Frydenberg’s comments are the latest by right-wingers who have grown angry by Mr Abbott’s antics, which over the past 10 days have involved his delivering speeches to think-tanks and the Liberal Party faithful, as well as a series of radio interviews where he has outlined an alternative conservative manifesto.

Mr Turnbull’s own frustrations surfaced on Wednesday when he repeatedly refused to utter Mr Abbott’s name during a radio interview, referring to him as a “gentleman”.

Acting Labor leader Tanya Plibersek seized on that to label Mr Abbott the “Lord Voldemort” of the Liberal Party, a reference to the Harry Potter novels where characters are afraid of saying the villain’s name.

While Mr Abbott has insisted that as a backbencher he has a right to speak out on issues and articulate conservative values, a leaked recording of comments to supporters in his seat of Warringah on Tuesday hinted that the former PM recognised he was on thin ice.

“At some point in time, whatever misgivings we might have, we swallow them and we get on with the job, which is trying to make sure the Turnbull-Joyce Coalition gets re-elected.” News Corporation quoted Mr Abbott as saying.

As well as ongoing tension over the leadership, the Liberals are under pressure from the Nationals over rural seats, with the prospect of three-cornered contests in seats such as Eden-Monaro, which has traditionally been the preserve of the Liberals. Deputy Prime Minister Barnaby Joyce defended the raid, saying the Coalition agreement clearly stated that in seats not held by a Coalition MP, either party could choose to run.

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Acting Labor leader Tanya Plibersek has labelled Tony Abbott the "Lord Voldemort" of the Liberal Party. PHOTO: AAP
Conservatives owe Libs nothing

Politics

When political parties abandon the task of policy leadership, they start to lose the reason for their existence.

John Roskam

When Immigration Minister Peter Dutton urged “rusted on conservatives” to continue supporting the Liberal Party he was giving voice to the hopes of every federal Liberal MP sitting on a close margin.

The trouble is that while Dutton wants the support of “rusted on conservatives”, his party haven’t returned the favour.

Under Tony Abbott, “rusted on conservatives” saw the Liberals increase the top marginal rate of income tax and abandon the cause of freedom of speech.

Under Malcolm Turnbull “rusted on conservatives” have seen a Liberal government raid their superannuation, implement an arbitrary tax that’s reduced the value of the bank shares they own, and promise higher income tax rates by increasing the Medicare levy.

Those “rusted on conservatives” who while not personally affected by these Liberal policies, nevertheless still believe that old conservative chestnut – “you can’t tax your way to prosperity”. Many will have looked at the most recent budget papers and seen that over the next five years the taxes and revenue collected by the federal government as a share of GDP will grow by 10 per cent.

A “rusted on conservative” with a grandchild among the 700,000 Australians who are unemployed sees a Liberal government doing not much to reduce the barriers to young people getting a job.

When “rusted on conservatives” raise these issues with Liberal MPs they usually get one of two responses – “At least we stopped the boats” or “Labor will be worse”. This is not to say there haven’t been some Liberal achievements. Abbott repealed the carbon tax, and on freedom of speech Turnbull went further than his predecessor dared. But, overall since the Liberals came to office in 2013, it’s been pretty slim pickings for “rusted on conservatives”.

Indeed it’s been pretty slim pickings for anyone who believes that a Liberal government should argue for their principles instead of just copying Labor.

When Abbott talks of the Liberals being at risk of slipping their philosophical moorings he’s reflecting the views of not only “rusted on conservatives”, but also how economic liberals see the Liberal’s policies such as the bank tax as fundamentally wrong and as preparing the ground for even worse measures from Labor. Which is exactly what happened when the Labor administration in South Australia introduced its own version of what Treasurer Scott Morrison did.

The fact that it was under Abbott himself that the Liberals’ philosophical slippage started is absolutely true. But that doesn’t negate the merits of the arguments Abbott is making. And in any case, Turnbull promised to be better than Abbott.

Turnbull promised to lead a “thoroughly Liberal government”.

“Rusted on conservatives” – and many other kinds of voters beside – can easily appreciate the simple points Abbott made last week. “We have an abundance of energy – but the world’s highest power prices; an abundance of land – and property prices to rival Hong Kong’s; some of the world’s smartest people – yet with school rankings behind Kazakhstan.”

What worries “rusted on conservatives” is that for the time being there’s no sign the Liberals are going to improve. In a speech a fortnight ago to the Liberals’ federal council, Morrison said the Liberals would no longer “slavishly follow past political orthodoxies, simply because they worked before”. This statement would have been a concern to anyone who thinks that the “past political orthodoxies” of economic reform under Hawke, Keating and Howard were actually pretty good for Australia.

The last time the Liberals warmly embraced a strategy of just giving people what they wanted the party was led by Billy McMahon.

In his speech, Morrison basically said that from now on the Liberals would forget about arguing for their political principles and would concentrate instead on giving the people what they want. At one level that’s unobjectionable. Democracy is all about the government reflecting the will of the people. But for Australia, we have a problem when giving the people what they want is unaffordable, and when 51 per cent of the people receive their income from the taxes paid by the other 49 per cent.

When political parties abandon the task of policy leadership, they start to lose the reason for their existence.

John Roskam is executive director of the Institute of Public Affairs.

Democracy is all about the government reflecting the will of the people.