3 A challenge in Russia

‘We were being given the run-around because some people didn’t like the idea of a hospice, while others were trying to get their hands on a project which they saw as a way to wheedle money and goods out of the West.’ Victor Zorza

Changing times

Zorza was astonished. To be allowed into Russia beggared belief. For years the Party hierarchy had been irritated by his analysis of East-West relations, published worldwide in his newspaper column, Communist World. For all that, his visa application had been granted.

As his plane touched down in Moscow en route from India to England, he wondered what he would find. His last memory of Russia was of crossing into Persia (Iran) in the spring of 1942, more than 46 years earlier. Then, he was with his compatriots, Polish civilians and military personnel, released from Soviet labour camps after Stalin’s amnesty the previous year. They were difficult times for an impressionable teenager. But what now, in 1988?

In fact Zorza found a country in decline. New forces had been unleashed that would soon lead to the collapse of the Soviet Union. This massive upheaval, both political and social, was on a scale unprecedented since the 1920s and owed much to the unintended legacy of Leonid Brezhnev.

After Nikita Khrushchev fell from power in 1964, Brezhnev had invested heavily in defence, allowing the country to stagnate economically. Freedom of expression was limited, religion was suppressed and dissenting voices were silenced. And outside of Russia, the ‘Brezhnev doctrine’ legitimised the use of force to prevent its allies turning away from Communism.

When Mikhail Gorbachev became general secretary in 1985, he inherited a daunting range of problems. Priorities at home centred on the waste of resources, widespread poverty and endemic corruption. Abroad, the war in Afghanistan had become exhausting. He writes:

By the mid-1980s our society resembled a steam boiler. There was only one alternative – either the Party itself would lead a process of change that would gradually embrace other strata of society, or it would preserve and protect the former system. In that case, an explosion of colossal force would be inevitable.

In an attempt to loosen the social constraints, measures
which became known as *glasnost* (originally ‘freedom of speech’ but later associated with ‘openness’) and *perestroika* (‘restructuring’) were designed to invigorate the economy by increasing the flow of goods and information. As these measures were introduced, oppressive practices declined and debate was encouraged. Dissidents were released and emigration restrictions eased; Jews left the country in their thousands bound for Israel or the US. By 1989, Soviet troops had withdrawn from Afghanistan. The following year, in a ground-breaking series of events, Russia declared its independence\(^5\) and Boris Yeltsin became the country’s first democratically elected president.\(^6\) In this new climate of openness, previously classified papers were placed in the public domain. As a result, Stalin and his policies were seen in a new light by a different generation, his criminality exposed to public scrutiny.\(^7\) In a speech to the conference of Russian Communists in 1990 – repeated at the 28th Party Congress two weeks later – Gorbachev criticised the years of political impotence and the absence of much-needed reforms:

> At the 20th Party Congress\(^8\) we heard truths that shook our country, the socialist community and the world Communist movement. What we learned then about Stalinism was an insult to the ideals that inspired generations of our people, that aroused them to revolution, to great construction projects, to the defence of our homeland, and to the rebuilding of our destroyed nation. The shock was enormous. One would think that a natural result would have been profound social and political changes. And although we cannot say that nothing has changed since then, unfortunately, the hopes for radical transformation were not realised. Even worse, crimes gradually began to be called mistakes, instead of reforms, there was tinkering with that very same bureaucracy instead of striving for new ideas: we merely updated the old Stalinist textbooks. All this caused festering wounds both in our society as a whole and in people’s hearts; it poisoned ideological life, and aggravated international relations. Eventually, the logic of political struggle led from half-truths to the hushing up of the past, from condemnation of Stalin to backsliding – to the rehabilitation of Stalin in various forms. The inevitable result of all this was political impotence and stagnancy in all areas.\(^9\)

Such rhetoric combined with Gorbachev’s innovations to produce a vision of the future unfettered by the shackles of the past; signals that were quickly recognised in Eastern Europe and the Soviet republics. As Communist governments were pressured to reform another view emerged: of a future free from Russian domination. Alarmed by Russia’s weakened position, conservative elements in the military forged an alliance with disaffected Party members to stage what became known as the August Coup (1991). Within

*Mikhail Gorbachev: ‘our society resembled a steam boiler.’*
days the coup had failed and a new star had arisen – that of Boris Yeltsin. When Gorbachev was ‘rescued’ from his dacha by Yeltsin, his political impotence was assured; from that moment, he became the highest profile casualty of Yeltsin’s success. For many, the choice was clear cut:

Yeltsin surrounds himself with democratic forces and people tired of Communism. Gorbachev promotes the scoundrels to the highest posts in the land. Yeltsin issues decrees to loosen the deadly grip of the Party. Gorbachev issues undemocratic decrees that are simply unconstitutional. The smartest people take Yeltsin’s side; Gorbachev’s team consists of fools and knaves. Gorbachev falls victim to his own intrigue, casts the country into danger and nearly perishes himself. Yeltsin, in unequal battle with no weapons, wins the day, and saves the life of Gorbachev and his family.¹⁰

On a tide of popular support, Yeltsin seized the assets of the Communist Party and recognised the independence of the Baltic States – previously part of the Soviet Union – whereupon Ukraine declared itself independent. By the end of 1991, Gorbachev had resigned as president, the Union of Soviet Socialist Republics had been dissolved and the Commonwealth of Independent States had come into being.

Against the backdrop of these changes, Zorza sought to establish the Russian hospice movement – a complex task exacerbated by the effects of soaring inflation and economic collapse. While the scale of the crisis is difficult to measure – due partly to a national tendency to overstate production during the Soviet days of subsidies, and understate production after the move to tax liability – one commentator gives a glimpse of its meaning for the Russian people. In a report aimed at the voluntary sector (1993), Lena Young writes:

In 1985, annual inflation stood at 4.6 per cent in the Soviet Union, in 1990 at 19 per cent, by 1991 at 200 per cent. Recently it passed the 2,000 per cent mark … The wholesale price index rose by a factor of 34 in 1992, the retail price index by a factor of 26. If in December 1991 an average salary bought you a refrigerator, in December 1992, you needed six salaries to do so.¹¹

This economic decline continued with devastating effects on living standards during the 1990s, leading to devaluation of the rouble in 1998. Alongside this decline was a fall in wages: in 1992, the minimum wage stood at 22 per cent of the minimum subsistence level and by 1998 it had fallen to 8 per cent. As a result, 60 per cent of the workers in health care and agriculture received wages below the minimum subsistence level.¹²

These developing trends convinced Zorza that if hospice care was to gain ground in Russia, funding must be both local and embedded in the state system. Though funds would be difficult to access, transitional support from the West could
only lead to temporary provision that would disappear when the funding stream dried up. The task he faced, therefore, was how to establish a form of care, previously unknown in the country, which would focus upon the needs of the dying and become sufficiently accepted to be grafted onto the state system of health care; a daunting prospect.

Zorza knew it would not be easy. No-one had heard of hospice; the word did not exist in the Russian language. So how would he convince an impoverished society in a country entering free fall to divert precious resources to the most unproductive of groups: the dying? Was Soviet medicine not focused exclusively on the living and based on a single criterion of success – the preservation of the workforce? In such circumstances, it would take a monumental change in attitudes for hospice care to become valued.

Despite the difficulties, Zorza felt compelled to embark on his fourth and last mission. It was something of an obligation. He recalled the shelter he had received from Russian peasants as he train-hopped along the trans-Siberian railway in 1941. As war waged all around him, he gratefully accepted the meagre portions of food, hastily prepared for him, as he headed deeper into Russia. Alone and afraid – and desperate to avoid a return to the labour camp – he knew that his presence spelt danger for his benefactors.

Now, after 40 years in the West, he was moved by the unrelieved suffering of the Russian people, especially the sick for whom medicine ‘could do no more’. Once their disease passed the point of cure, patients were fortunate to receive anything but the most basic care. Pain went untreated, and ‘a patient’s sense of hopelessness, isolation, guilt, frustration, fear, depression, and a hundred other social, psychological and spiritual problems were also ignored.’ When Zorza entered a housing block, he recognised the cries of the sick, overwhelmed by their pain: cancer a terror, suicide the all-too-frequent response. In his book, Cancer Ward, Solzhenitsyn describes the state of those without hope:

The last month I hadn’t been able to lie, sit down or stand without it hurting, and I was only sleeping a few minutes a day. So I must have done plenty of thinking. This autumn I learned from experience that a man can cross the threshold of death even when his body is still not dead. Your blood still circulates and your stomach digests, while you yourself have gone through the whole psychological preparation for death – and lived through death itself. Everything around you, you see as if from the grave.

Among the many changes in this country of 144 million, life expectancy for males declined by six years to 57.6 between 1990 and 1994; during the same period, mortality for males in the 40–49 age group increased by 87 per cent. Between 1995 and 2001, the Russian population fell by 5.5 million. Currently around 60 per cent more are dying than are being born – a rise in the rates of mortality unprecedented in a twentieth-century industrialised nation.

It had not always been thus, especially during the heyday of Soviet Socialised Medicine. SSM emerged from the revolution of 1917 which itself followed three years of bloody war in Europe. Epidemics had taken a heavy toll and a population weakened by hunger – and lacking in fuel and basic disinfectants – faced an uphill struggle against typhus, causing Lenin to declare: ‘Either the louse [carrier of typhus] conquers socialism or socialism conquers the louse.’ Driven by a determined leadership, the Soviet Union became the first country in the world to provide health care to the entire population as a public service funded from the state treasury. From the establishment of the centralised Shemasko model in 1918, health initiatives were driven by the ideas of the social
hygienists. The focus, therefore, became preventive and social rather than clinical or remedial. Success was dramatic and huge gains were made in the control of infectious diseases such as tuberculosis, typhus, malaria and cholera.

Yet these achievements were not reflected in the health status of the population. The focus on infectious diseases overlooked the impact of cancer, cardiovascular and other non-communicable diseases. The development of a pharmaceutical industry was given low priority and ineffective treatments remained routine despite contrary evidence. Importantly, the Soviet philosophy of paternalism encouraged attitudes of dependency rather than responsibility and lifestyle issues connected with diet, smoking and alcohol use were neglected – a situation exacerbated by reliance on alcohol sales as a means of boosting the economy. Moreover, despite the rhetoric that every citizen had access to a medical facility, the quality was variable and poor in many rural areas. In this culture, cancer became unmentionable and death unapproachable. In 2001, Irene Salmon, a British nurse who worked in Russia from 1996–98 commented:

There is a very strong death/dying taboo in Russia, and an even stronger cancer taboo … In Soviet times it was illegal for a doctor to tell a patient of a diagnosis of cancer. This law was only recently repealed, so doctors remain reluctant to communicate this information to patients.

A key consideration for Zorza was where to locate the hospice service in the Soviet health care system. This decision was crucial since two schemes of care operated in tandem, one accessed on the criterion of residence, the other by rank. The Residential Network served the majority of the population and each person knew the polyclinic assigned to their address. The Closed Network was reserved for the nomenklatura or other citizens of rank who had access to an altogether different type of care. These closed facilities were:

... reserved for the members of the different elites, culminating in the hospitals, clinics and rest homes of the Kremlin (called the Kremlinovka) where the highest officials (and their families) had access to the best medical care, equipment and buildings available in the country. In some instances patients could also be sent abroad for treatment. These palatial facilities, the equivalent of private hospitals and clinics in the West, were considered as perquisites of rank.

Providing a gold-standard hospice service to cater for the elite was abhorrent to Zorza, so he quickly adopted the residential model rather than that of rank. In his view, the principle was non-negotiable and fundamental to the integrity of the service. Yet tensions arose when St Petersburg’s second hospice opened at Kolpino and the management took a different view. From that moment, admission criteria became a contested area. Zorza:

While continuing to work and spend a lot of time in Leningrad to make sure that hospice developed in the right way, I shifted my focus back to Moscow and divided my time between the two cities. In the meantime a Russian doctor, without any support or knowledge on my part, set up a hospice of her own [at Kolpino], without funding from the state, and without observing the principle of admission only from the district where the hospice was situated, and of course immediately there were stories about paying in order to get in.

Defiance was intolerable. As the self-appointed guardian of the hospice ideal, Victor was anxious to ensure that his principles were followed by all who were drawn to this new approach. After all, these fundamentals had become encapsulated in the memory of Jane’s death and were thus
rendered inviolable. ‘He treated us like his children,’ recalls Nina Khmeleva, one of the first doctors to work in a Russian hospice, ‘and he told us what we must do.’\textsuperscript{25} This was no exaggeration; Victor demanded unquestioning commitment. Speaking of a doctor who had both clinical and managerial responsibilities, he declared: ‘I did not want bureaucrats. I asked her: “Could she guarantee that when she goes back she will become a hospice doctor and resign from her administrative position?” And she um’d and she aah’d.’\textsuperscript{26}

If Victor was chagrined by the events at Kolpino he reached a compromise over Tula. It was here, in a region contaminated by the explosion at a nuclear plant in Chernobyl (Ukraine) during 1986, that Russia’s second hospice opened in 1991. Influenced by the independence of British hospices, and fearful that in Russia a service offering upgraded care could be appropriated by the bureaucratic remains of SSM, Zorza counselled against integration with the current health system. Yet he supported the developments at Lomintsevsky Hospital (Tula) where a second-floor ward was converted into a hospice unit.

A key factor at Lomintsevsky was that funding came from the central health budget of the Tula region, 2.8 million roubles in 1993, and Zorza was impressed by the high level of capital investment. Refurbishments had given the ward a homely atmosphere. A new heating system had been installed. A kitchen and sitting room – fully furnished, decorated and equipped – provided welcome facilities for patients and relatives. A chapel was established. Bathrooms and toilets were upgraded and a new sterilisation unit installed.\textsuperscript{27} Importantly, the inspiration behind the service, Dr Elmire Karajaeva, had attended Victor’s training course and he became convinced of her probity:

She was running a small clinic there and we checked her out very thoroughly. We made sure that she was, in fact, getting funding from the local health authority. We watched her during the course and she was good; and she went back to Tula after the course and converted her small clinic into a hospice. Because she was a good person, we made an exception to another rule that I’d established, which was that we did not want hospices to be directly associated with a pre-existing medical establishment, either on the premises of one, or subordinate to one, or directly associated with one, because we feared the contagion that we felt would inevitably spread – which certainly existed in almost every medical establishment – and which would inevitable spread to the hospice if the hospice was part of one. But she obeyed our rules, even though she was running this other clinic, a general clinic, and so far it seems to have worked alright.\textsuperscript{28}

Whether or not Elmire Karajaeva followed the detail of Victor’s rules, the point is that the first two hospices in Russia – Lakhta and Tula, represented different models of
care: the free-standing hospice and the hospital-based unit. One independent from existing health facilities, the other totally embedded. In typical fashion, once he had decided to support Tula, Zorza looked for benefits. Could a comparison be made between the two models which would inform future strategy? Wendy Jones tells how his plans developed:

His idea was that two [hospices] should be free-standing, that is, hospices separated from the hospitals but deriving their incomes directly from the health committees of the Soviet cities – and that two should be incorporated within the bounds of an established hospital, and therefore deriving their income via the hospital budget (although ultimately it still comes from the health committee) so that the difference would be two free-standing hospices operating independently of a hospital and the others within a hospital. And as far as I understand it he wanted those two models set up in order to be able to compare which form and which structure would be the better for Russia.29

The review never took place because Victor died in 1996 before it could happen. Yet both models gained support. Around 60 free-standing hospices (including hospice projects) and 30 hospital-based units were identified throughout...
Russia in 2004. As the debate around the merits of each type continues, the World Health Organisation has taken the view that in resource-poor areas, hospice and palliative care provision can be maximised by utilising health care systems already in place. In the largest geographical country of the world, this suggests that if the hospice approach is to reach the dying poor throughout Russia, such opportunities should not be overlooked – a point that Victor, despite his reservations, had already noted.

Yet his caution was justified. Among the structural problems faced by hospices were the effects of chronic underfunding. After independence, the Russian health system still bore the hallmarks of Soviet medicine and sat uncomfortably with decentralisation and the introduction of insurance-based models of reimbursement. An overall lack of direction had combined with political instability to produce a guarded inertia among the workforce which convinced Zorza that the best way forward was to maintain a protective distance between hospices and formal health systems. Cocooned in the ethos of the hospice, this would encourage activists to adhere more closely to the collaborative approach that placed the patient centre stage.

Ever astute, Victor realised that this goal would need special attention. The concept of the multidisciplinary team was foreign to the paternalistic structures that supported a physician-led model of care that generally lacked input from allied professions. Andrei Gnezdilov:

In the hospital at that time there was a very strict hierarchy: you had the head doctor, then his vice, then doctors, then nurses, then care assistants and only then the patient.

Breaking down these structures would require health professionals to see beyond their status and recognise the value of other contributors. Education would ease the nervousness of those who felt vulnerable after abandoning the certainty of their position – and Victor had already made plans for both Russian-based and British-based courses. More difficult to achieve would be the hearts-and-minds acceptance of patient autonomy, since this struck at the core of the doctor's ethical code. During Soviet times this code emphasised the doctor's relationship to the state and remnants of these duty-focused ethics have left a detrimental legacy to palliative care development:

Most of Russia's bioethical standards and behaviour stem from two important features of deontology. One is the physician's oath. In the former Soviet Union, that oath required physicians to protect first the interests of the State, not the interests of the patient. This conflict between responsibility to State and patient often worked to the patient's
detriment, and it is diametrically opposed to principals of physician responsibility in other countries. The second influential feature is the fundamental deontologic principle that obliged Russian doctors to protect patients from knowledge of potentially fatal diagnoses. This rule required that physicians not reveal diagnoses such as cancer, and it had the further effect of quelling communication with patients generally.\(^3^3\)

Pain relief was a special concern. If pain was to be effectively managed, medical practitioners and drug controllers would need to reassess their attitudes towards opioids. Strict regulations and fear of addiction inhibited the use of morphine which, at the beginning of the 1990s, was only available in injectable form. Speaking of Russia’s isolation from palliative care developments in the West, Wendy Jones comments:

Knowledge of pain relief [in Russia] was scanty in the extreme, and coupled with that was the non-availability of analgesics. So there was huge resistance to any use of opiates and very, very strict legislation against it, and minimal doses allowed; that’s beginning now to be somewhat easier. The Russians are now much more aware of what’s needed, and the doctors, in places, are fighting to get the right sort of doses for their patients; so there’s been a move forward in that respect. But in the initial stages the non-availability of analgesia and the poor understanding of how it should be used was a big problem, added to which the management of all the symptoms compounded the whole sorry state for patients.\(^3^4,3^5\)

Zorza would campaign vigorously for the easing of restrictions so that palliation could be achieved within the hospice context. Remarkably, morphine consumption between 1994 and 1998 rose from 344 kilos to 1,377 kilos and, during the same period, the average defined daily dose\(^3^6\) per million inhabitants stood at 160. Despite this figure being the highest, at that time, among the Commonwealth of Independent States, it compares unfavourably with other countries in Eastern Europe such as Slovakia (583), Hungary (509), Poland (486) and the Czech Republic (388).\(^3^7\)

As Victor embarked on his Russian venture, he was acutely aware of the effort that lay ahead and the pitfalls along the way. More than most, he also knew the personal price he would have to pay to combat the effects of practitioner-led resistance and government intransigence. Hospice care would not fit seamlessly into existing health systems – nor would he want it to – and he rightly anticipated that his advocacy for the dying would in many cases fall on deaf ears. But he was convinced that, like him, relatives who had stoically cared for family members and fretted over their suffering with a heavy heart, wanted something better and that, given the opportunity, there were health professionals waiting to become involved. There would be no going back.

**Avoiding corruption**

Zorza’s initial plan was to open a hospice in Moscow. In late Soviet Russia this would require two things: a ‘sympathetic ear’ within local government and a decision by the health authorities to allocate premises. Victor was aware that such commodities came at a price, but he was keen from the outset to keep hospices untarnished. It would take some doing, since Zorza believed corruption to be endemic at every level from government to service delivery. Eileen Lerche-Thomsen, Victor’s partner during the 1990s, recalls his stance:
[Victor was] very concerned to mark out the hospices as something completely different from the general run of medical care in Russia, which in his view was riddled with corruption; where you had to grease palms to get things done. If you had money and influence, you could get the best kind of treatment that was available, but for the vast majority of the population you might even have to pay a bribe to get a bedpan. So he was utterly determined that hospice, which he saw as the purest kind of genuine, compassionate caring for individuals – regardless of money, or rank or anything, would be free of it.\(^{38}\)

In this respect, Zorza’s rectitude and tenacious spirit stood him in good stead. Wendy Jones:

Victor did a lot of what he could do by virtue of his personality and his huge knowledge of Russia. From his journalistic days, he knew Russia and he knew the culture and, of course, he knew the language perfectly. He knew how to get things done. He knew when to stamp his foot and all sorts of things.\(^{39}\)

He needed, though, someone in situ that he could trust: a person who understood his approach and who could help him gain access to the political machinery. There were two problems here: first, where to find such a person; and second, whether he could allow himself to trust someone else. Paul Rossi, treasurer of the British Russian Hospice Society:

I think because of his background, Victor wasn’t a terribly trusting person and there were very few of us, I think, he trusted to do anything properly. And I think saw a bit of dishonesty in everyone. And I remember there were a number of opportunities where we could have worked with others, but he didn’t want to because something in the other person’s background made him suspicious; and it could have been something absolutely without much significance.\(^{40}\)

Victor’s answer was to seek help from the world he knew – the media. Reviewing his networks, he fixed on the chief editor of *Izvestia* and made an approach. It was a shrewd move. The paper was the government’s official publication and had its roots in the earliest days of the revolution, when it appeared as a daily of the Petrograd Soviet of Workers’ and Soldiers’ Deputies (1917). The editor responded by asking a reporter, Inessa Slavutinskaya, to do what she could to help Zorza. She agreed, but on meeting him, had serious misgivings:

The first thing I told Victor was that I thought it would be very difficult for us to work together, especially for him, because I also have a very strong personality.\(^{42}\)

They clashed many times; but they also established a close working relationship and Inessa invited Victor to move into the flat she shared with her husband Felix and their son Anton. It was small and cramped, but they could talk at length and Inessa was on hand to help Victor fine-tune the details of his strategy. She recalls:

He stayed at my house because I have two rooms for my husband, me and our son. Victor told me ‘it is so expensive to live in the hotel’ and it was the first month, maybe, after we met. And I told my son, ‘OK, Anton, please, let Victor live with us,’ and me, my husband and my son lived in one big room and we gave Victor the other, the room of our son.\(^{43}\)

When meetings were arranged with local dignitaries, Inessa invariably attended. Not only was she on hand as interpreter, if required, but she monitored the tone of the meetings and gave Victor cues on how to proceed. Sometimes, his passion would get the better of him and when this happened, his uncompromising approach became even more assertive. Inessa:
He was very strong-willed and sometimes – sometimes it wasn’t good. I tried to explain to him the Russian mentality because Victor was very aggressive to our authorities. I told him: ‘OK, Victor, you will sit beside me and if I feel that you become angry, I will kick your leg.’ It was a very good idea. But after each meeting he told me: ‘Oh, Inessa, my legs are black and blue!’ But he had to be polite. For instance, with the minister of health, Victor said: ‘I know what you have to do.’ And the minister answered him: ‘I live in this country and I’m the minister. I know what to do.’ ‘You know nothing!’ said Victor. So the minister said: ‘Goodbye, Mr Zorza!’

In such circumstances, progress was impossible. After strenuous efforts to succeed in Moscow, Zorza accepted defeat and turned his attention to St Petersburg. He was bitterly disappointed. It would be 1994 before Moscow’s home care service began and another three years before the in-patient unit opened. He would not live to see it. As he considered the barriers to success in Moscow, corruption figured prominently:

We started in the late ‘80s in Moscow and found that the corruption was so overwhelming and the bureaucracy was so absolutely – not just corrupt, but at odds with each other – that again and again we failed. Over the years we were on the point of having a hospice in Moscow and four times it collapsed because of those nefarious influences.

Such influences continue to date. Commenting on Moscow’s commercial and property development, Georgy Bovt, deputy editor of Izvestia writes:

Moscow’s construction boom is also a bribe-taking boom. The treatment of historical buildings by the Moscow authorities is completely focused on finding ways to exploit them commercially. There is no rule that won’t be bent, or forgotten entirely, with the amounts of money at stake.

Victor’s experiences confirmed his worst fears and fired his determination to found a ‘pure’ service. As plans were made, the potential for corruption became a central issue; an obligatory consideration at all levels of development and policy. At the same time, aid and investment was flowing east. As Communism collapsed, companies in the West were dazzled by the array of new opportunities and scrambled to establish a foothold in developing markets. Professionals offered wide-ranging support to bring their Eastern European counterparts up to speed with Western skills and technology. In the euphoria surrounding new-found freedoms, Zorza’s warning seemed at best to be overcautious.

His concerns, though, were well founded. As aid poured into Russia, stories arose about misappropriation on a grand scale. Figures from Goskomstat, the state statistics committee, show that in 1992 the Russian government received 510,000 tons of humanitarian aid – of which ‘the needy’ received 89,000 tons; the rest was sold. Similar activities were discovered among charitable organisations. Lena Young, in her 1993 report about the operation of charities in Russia writes:

No sooner had post-totalitarian charity been born than there were revelations about instances of gross mismanagement and dishonesty in certain voluntary groups. These reports negatively affected public opinion about the voluntary sector as a whole and gave rise to persistent suspicions about ‘yet another mafia’ disguised as a charity. Doubts about charity are confirmed when stories appear about nasty thefts of humanitarian aid. For example, the head of Children’s Hospital No 4 in St Petersburg diverted virtually trainloads of German humanitarian aid into her own commercial outlets. She did not let one aspirin reach the children for whom the aid was intended, an action that smacks of more than
simple dishonesty. As a result of this exceptional greed she was caught and imprisoned for five years.\textsuperscript{48}

Within health care, Victor had seen for himself the invidious practices facing patients and families. In typical fashion, he had researched the field by immersing himself in the system, thereby distinguishing the reality from the rhetoric. His unobtrusive presence took him to the bedside of patients and opened his eyes to the daily routine of Russian health care:

My first attempt to gain familiarity with the system consisted actually in going into hospitals, into the homes of terminally ill people and sitting around and helping, just as an ordinary volunteer, to see what goes on. And many were the times when I saw a patient peeing into a vessel and putting it under his bed and asking the orderly to carry it off and to empty it because he had more coming – and the orderly would ignore him unless he’d been given a bribe. So it penetrated the whole system; and that of course is something that you must not, cannot possibly have in a hospice: it wouldn’t be a hospice if you had it.\textsuperscript{49}

Whatever name is ascribed to this practice, direct payments of one sort or another have become deeply embedded in Russian health care culture. They originated in the early years of Communism when the salaries of doctors’ were fixed at an artificially low level.\textsuperscript{50} At the close of the twentieth century, medical practitioners and other health workers still had low incomes – and the practice of direct payments had been established over decades. Yet these sorts of payments are not only found in Russia; they are commonplace throughout the countries of Central and Eastern Europe.\textsuperscript{51} Described as a ‘gratitude for service’ – and supposedly unrelated to a fee – the ethical implications of the practice are obvious:

It discriminates between rich and poor … and divides physicians beyond the possibility of reconciliation. Thus, the medical profession is divided, the patients are uncertain whom to pay, when and how much, and are exposed to the mercy of the system.\textsuperscript{52}

To Zorza, hospice care symbolised the highest form of human endeavour so it was worthy of the strictest measures to guard against exploitation. Bribery and corruption had no place, and the way to keep such elements at bay was to control the flow of funds. Five areas were identified wherein the organisation could be vulnerable: capital expenditure and running costs; patient admissions; charitable donations; ‘gratitudes for service’; and staff training.

Victor’s first principle was that Russian money was essential; he intended, after all, to establish a movement not a building. This required not one but a network of hospices which operated collaboratively throughout the region. Although foreign funds may be raised for one hospice, the running costs of a network would be impossible to sustain, even if the capital costs were forthcoming. But there was another consideration. ‘If we started with foreign money we would never live it down, because people would get used to this idea and they would always expect it.’\textsuperscript{53} Funding from the state, therefore, was essential. And this ruled out any unregulated flow of funds from abroad.

As we have seen, Zorza shunned the idea of providing a facility for the nomenklatura on egalitarian grounds, though this decision also provided a safeguard against bribery:

Because the propaganda we had built up about the excellence, the uniqueness, of a hospice was so powerful, the danger was that people would pay anything to get their loved ones into a hospice, which would of course subvert our staff, and pervert our concept. The device I developed
with the health authority [was] that it would serve only the administrative district of the city in which it was situated. We laid down the rule that the hospice would take anybody, but anybody, living in that district who in the judgement of the hospice’s doctors needed hospice care, without any payment, without anything. There would be no need to bribe, so long as you lived in the district. Anyone who lived outside the district – be it the prime minister’s mother, or the wife of the first party secretary of Leningrad (who as you can imagine was more important there than the prime minister) or the son of the richest man in the city (and by that time people were beginning to make fortunes) – if he did not live in the Primorski district there was absolutely no possibility of admitting him. So again: no bribes because there was no point in offering it; there was no physical possibility because you couldn’t hide. I mean, we looked after patients as soon as they were discharged from hospital. We knew where they lived, we looked after them at home, and when the time and the need arose we would take them to the hospice; so nobody could kid us about where they lived. So that way, we prevented the pressure of bribes for admission which worked in other medical establishments.

54 For all the widespread poverty some individuals were making fortunes. In the failing economy, empty shops and long queues were circumvented by hard cash. Everything had its price and health care was no exception. Where hospice had become established, better care for the dying was greatly valued and there was frequent competition for places. A policy was needed to nullify any advantage of wealth. Zorza continues:

We laid down another rule to prevent the temptation of – and the possibility of – pressure from the new rich. We said that we will not accept charitable donations from individuals – and especially from organisations, establishments, enterprises – unless they are entirely anonymous. We do not want to know who these people are because we do not want them then to come to us and say: ‘Look, we gave you this money, can you take my mother? Or my sister?’ Nor, also, because we knew how corrupt the business establishment was; how deeply it was penetrated by the mafia; how likely it was that within two or three years any of those businesses might find itself in court accused of all sorts of things. We did not want them to say: ‘Ah, well, we gave our money to the hospice,’ or to seek acceptance by the public on a plea that they gave their money to the hospice. So we said, ‘only anonymous donations.’ And it worked.55

55 So what of the ‘gratitudes for service’? In this instance, Zorza distinguishes between an unsolicited donation after the death of a patient and that iniquitous practice whereby the strong elicit payments from the weak for routine care:

We laid down the rule to prevent it happening once the patient was within the hospice. We laid down the rule that no offerings in money or kind could be made to the staff, or accepted by the staff, until the patient was dead. Then we would, of course, accept it if the family wanted to give us something; but we didn’t ask for it.

56 Victor also paid attention to staff training, an area that was prone to abuse. While the trainee’s skill and adaptability were important, motivation also played a part. These were changing times and opportunities for funded travel – especially to the West – opened new doors for the student. Rigorous vetting was essential:

I got Dr Twycross to organise a course in Leningrad, not only for the additional Leningrad doctors who work in that hospice, but also for doctors from all over the country who might establish hospices of their own. We tried to check them very thoroughly. We took a very, very long time in checking them out because, unless we get the right people for the jobs, they could be the very people who would undermine
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the hospice in the ways that other medical establishments were undermined from within by doctors who were ‘on the make, on the take’. There were about 35 doctors on the course. We rejected a great many before they came to the course because we found out things about them. I mean, even then we sifted them again when they arrived, and still sent several away. And during the course itself we still found that about a dozen were quite unsuitable, people not to be trusted for various reasons.57

In many respects, Zorza’s stance was a lone fight against institutional corruption in the face of overwhelming odds. Faced with this struggle, few would have had the tenacity or inner resources to persevere, comfortable in their isolation. Yet Zorza continued relentlessly, inching slowly towards his goal. Disappointment was brushed aside and his uncompromising stance ensured that this new initiative was not consumed by predacious forces, to disappear from view like so many other projects. Instead, hospice care retained its core, a recognisable essence that patients and health professionals alike began to warm to. Crucially, in the space that Zorza created between hospice and other health systems, the central ideal could breathe and grow.

A familiar strategy

The experience of promoting hospice in the US proved invaluable to Zorza in his work in Russia. Having successfully linked the story of Jane’s death to an extended hospice campaign, endorsed by influential luminaries, he adapted the model to suit the Russian context.

The first task was to publish *Death of a daughter* in Russian and for help with this, Zorza turned to his old friend, Nikolai Yefimov, the editor of *Izvestia*. Yefimov had already provided accommodation for Victor and allocated Inessa Slavutinskaya to assist with the project. To Victor’s surprise, Yefimov now made a bigger commitment: overall patronage of growing hospice developments. Twycross noted in a letter of 1990:

Zorza is now going ‘national’ with the publication by *Izvestia* – thought of as the best Soviet newspaper – of a series of articles on hospice by two of its star reporters in the second half of this month. The editor of *Izvestia* has promised that his newspaper will see it as its task to lead a national hospice campaign, to do it with tact and delicacy, and to stick with it at least five years.58

Though pleased with Yefimov’s offer, Zorza was quick to see the possibilities of wider support if the press could somehow be linked with the Church. So he contacted Patriarch Alexei to secure his agreement. The Patriarch concurred and Zorza wrote triumphantly:

Patriarch Alexei has accepted my suggestion that the Church should assume joint patronage with *Izvestia* – a partnership unique in Soviet history.59

Aleksandr Vasinsky and Aleksandr Krivopalov were *Izvestia*’s special correspondents assigned to the hospice story. ‘Dying the human way’ and ‘Living to the end’ are two of several articles published in 1990 which tell the story of Victor’s early life, the death of Jane, and the founding of the St Petersburg hospice. The reporters’ research had taken them to England to visit hospices in Oxford and Windsor. As a result, Victor’s advocacy was supplemented by thoughtful voices from the English movement and informed commentary from Vasinsky and Krivopalov. In their ground-breaking article ‘Say goodbye and depart’ the journalists state:
In England’s hospices, the fundamental rule is that the patient is the main person; his every need is met in an attempt to forestall his slightest desire. The outward appearance of the patients – the terminal patients – is astonishing; their hairdo, their clothing so unlike hospital clothing; their smiles; their neatness; a confiding sort of club atmosphere – friends among friends. 

In the article, Yvonne Johnston, the administrator of Thames Valley Hospice, Windsor, stressed the importance of keeping the patients within the community:

We didn’t want the hospice to be in an out-of-the-way place. It was important for it to be part of the town community, but nevertheless, that there should be plenty of open space so that people’s eyes should not be staring at walls, should have no obstacles in front of them – only space and sky.

Robert Twycross stressed the need for patients to feel safe:

The main thing our patients feel immediately is that they are under protection, that they are amongst their own people. As soon as they arrive, we as it were make it our duty to think about them always, for whole days and nights, both while they are alive and after they die. We think about them and their close ones. This immediately removes from the heart of a dying person a great weight of fear, of anxiety about the unknown.

The combined effect of these articles – made all the more emotive by reports from Lakhta and interviews with patients and staff – was to send shock waves through the Izvestia readership. Contentious issues were not overlooked. The hospice practice of truth-telling contrasted sharply with established practice; yet the issue was met head on:

The novelty of the hospices and the multitude of false rumours linked with it are included in the following rule: if a patient asks a doctor for his diagnosis, the truth will not be withheld from him. This is contrary to our medical ethic, to the concept about the humanity of ‘a lie to save’, about the practice of distracting a patient from the traumatic thoughts of inevitable death. In English hospices, there is complete openness between the doctor and the patient and his relatives; questions of dying are not only allowed, they are even encouraged. We’re not used to this, it is something – well, harsh.

Gnezdilov says we have lost the dignity of dying. Soviets have always been taught that everything’s going to be alright – aimed at life without end and a bright future. Modern science already knows how to make the last stage of a person’s life full of value. People come to the hospice not to die, but to live to the end. But for this we’ve got to abolish many of our stereotypes linked with the ideology of false optimism.

Such open rejection of Soviet ideology drew a group of influential thinkers and rising politicians towards the nascent hospice movement. Alongside new democratic principles, the hospice philosophy became emblematic of a moral perestroika and an overt expression of the more profound values of Russian life. It was a welcome volte-face that attracted national and international support.

In the West, Peter Ustinov was intrigued by the possibilities of this ideological shift which centred on the hospice movement. An interested observer of events in Russia, he linked the new movement to the emerging reforms and was pleased to appear alongside the distinguished academic Dmitri Likhachev in a written plea for hospice support. Little known outside of Russia, Likhachev was an eminent historian who had a strong affinity with Russia’s cultural and Christian heritage. His opposition to Stalin resulted in a four-year internment in a prison camp; on release he returned to
St Petersburg and the Institute of Russian Literature and eventually became chairman of the Soviet Cultural Fund. After Sakharov died, he was widely regarded as the conscience of Russia and an influential member of the Duma. The joint appeal by Ustinov and Likhachev was a substantial triumph for Zorza. Ustinov begins:

Soviet supporters of the hospice approach see it as part of the process of renewal.

Both Likhachev and Ustinov became key figures in the organisations established by Zorza to support the hospice movement. Likhachev became chairman of the Russian Hospice Society and president of the Leningrad Hospice Society. Ustinov was a founder member of the Leningrad Hospice Society and the British Soviet Hospice Society (later renamed British Russian Hospice Society). Anatoly Sobchak, a rising star of perestroika and the first democratically elected mayor of St Petersburg, was a founder member of all three societies. Orthodox leader Patriarch Alexei and Edvard Shevardnadze, Gorbachev’s minister for foreign affairs were members of the all-Russia society. Sobchak’s wife, Ludmila Narusova, agreed to chair the Leningrad Hospice Society. An academic with a background in history, she was an astute politician who became highly regarded as a deputy of the State Duma. Other members of the Leningrad Hospice Society
included Sharon Miles, wife of the US Consul General. The generic principles of each organisation replicated those of the all-Russia society: ‘The Russian Hospice Society is a not-for-profit organisation which provides care completely free of charge to all patients, regardless of creed, politics, race, or any other characteristic, particularly without regard to position in Society.’

Zorza’s recruitment to the British Soviet Hospice Society shows his now familiar attention to profile and balance. Led by the Duchess of Kent, presidents included The Archbishop of Canterbury (leader of the Anglican Church) the Cardinal Archbishop of Westminster (the most senior Roman Catholic in England) and the Chief Rabbi of the United Congregations of the British Commonwealth of Nations: an impressive trio to serve alongside Patriarch Alexei. Politicians included Margaret Thatcher (at that time prime minister) and Denis Healey – an elder statesman of the Labour Party. Founder members included the concert pianist Vladimir Ashkenazy, British TV presenter Martyn Lewis and Lady Braithwaite, wife of the British ambassador to Moscow.

Despite there being three hospice organisations founded by Zorza, he planned a fourth: the American Soviet Hospice Society. By 1991, Senator George Mitchell, Henry Kissinger and Sharon Miles had agreed to become founder members as had Yuli Vorontsov, a distinguished Russian diplomat with long-standing links with the United Nations. Moves were also afoot to recruit former members of the US-based Hospice Action Committee established by Zorza in the late 1970s.

In the summer of 1991 Victor found a new urgency when news broke of a forthcoming Russian-American summit to be held in Moscow during July that year – and the American President, George Bush, would be accompanied by his wife, Barbara. By this time plans were well advanced
for a government building in Moscow to be redesigned as a hospice. There was no time to lose and Zorza, in typical fashion, wrote directly to the First Lady at the White House:

Could you help a fledgling hospice movement during your coming visit to Moscow? The first Russian hospice opened last year in Leningrad and six more are planned for other cities. A course for nurses will be held in July-September in Moscow, where a ruin of a building is to be converted into a hospice. Could you lay the foundation stone and visit the course?

When Susan Porter Rose, chief of staff to Mrs Bush, sent an encouraging reply: ‘Your invitation to Mrs Bush to lay the foundation stone at the dedication of your newest hospice is under consideration,’ Victor realised the opportunities immediately. As a media attraction designed to publicise the hospice movement the occasion would be invaluable.

Never afraid to build a story around himself, Zorza had also written to Bernard Gertzman, editor of the *New York Times*. Gertzman had a strong interest in Russian affairs having served in Moscow as the paper’s bureau chief, and in New York as foreign editor, where he supervised the paper’s coverage of the fall of Communism. Zorza:

[The visit] could yield a strong *Sunday Magazine* piece for the *New York Times*. At its simplest, it could be a story about a journalist who used his daughter’s death to help others. But it could be much more than that, about life and death, a father and daughter, about the Soviet Union and the West, about Russia then and now, and about the Himalayas, whither I’ll be going back as soon as my Russian mission is accomplished.

In addition to the publicity value there was a unique opportunity for fund-raising. Yet herein lay a weakness – he lacked an American society through which to channel the monies. It was a serious problem. In view of the imminence of the visit, Zorza made a special case to his financial advisers:

The White House is giving favourable consideration to my invitation to Mrs Bush and will let me have a final decision soon. The US media publicity arising from the Bush visit is an unrepeateable opportunity to appeal to the public for donations, but we have yet to set up the American Soviet Hospice Society through which to collect such funds. Could we set up the Society now, before the Summit, pending the grant of a 501c3 number, acquire an accommodation address and ask for contributions to be sent there?

We will be appealing for donations to pay for medicines and equipment, for the training of staff by Western hospice doctors and nurses, and for the building of several hospices as centres of excellence from which the concept and practice may spread throughout the Soviet Union.

Victor’s letter was dated 17 July 1991. The summit took place at the end of that month and on 31 July, the historic Strategic Arms Reduction Treaty (START) was signed in Moscow: George Bush for the USA and Mikhail Gorbachev for Russia. The laying of the Moscow hospice’s foundation stone, however, did not appear on Barbara Bush’s itinerary. A month later, the August Coup stalled further progress and the designated building never materialised. The project was abandoned amid great disappointment.

Despite some acknowledged benefits, Victor’s fondness for recruiting dignitaries was sometimes seen to be peripheral to the main thrust of hospice development, and, in some circumstances, counter-productive. Publicity material for a proposed auction of art works included a letter signed by Likhachev, Ashkenazy, Brodsky, Patriarch Alexei and Shevardnadze. Still not satisfied, Zorza wrote to Sotheby’s, the proposed auctioneers: ‘I’ve been told by some Russians who think they know about such things that it would help if the
letter was signed by Mrs Thatcher and Anne Getty … Any views? ’ Overdoing things!’ came the reply.

Stephen Connor echoes this sentiment in relation to the US movement:

I think our efforts were to try and create a national organisation pretty much from the ground up. In some ways it helps to come at it from both directions and Victor knew a lot of prominent people. I think his preference might have been to create a higher level board, whereas we wanted to get all the hospices that were involved in the United States at the time together, and let them create an organisation, develop standards. In fact the governance of NHO – which is now the National Hospice and Palliative Care Organisation – the majority of the board are elected from the provider membership.

Negotiating the Russian bureaucracy, however, was a painstaking process that was greatly eased by the sponsorship of key players. While this angered some lower ranking officials, Zorza knew the system and was prepared to use it to his advantage. Gnezdilov:

Victor realised that you couldn’t get anything done in the bureaucratic system and so he went to the important people, and became very well known. Everybody knew him; people like Sobchak and Shevardnadze, our foreign minister. But Victor made enemies because he wasn’t prepared to be passed from one person to another at the lower levels; and sometimes people only did what he asked, or accepted him, because of who he knew at the higher levels.

Meeting people was an important part of this process and here, Zorza turned for assistance to the wives of diplomats: Sharon Miles (wife of the US consul general), Rebecca Matlock (wife of the American ambassador), Mary-Lee Katzka (wife of the head of Cultural Section and personal assistant to Rebecca Matlock) and Lady Braithwaite (wife of the British ambassador). He had a carefully considered approach, as shown in this letter to Mary-Lee Katzka:

I have just arrived in Moscow from Leningrad where we recently opened Russia’s first hospice, with the active participation of Sharon Miles, who became a pillar of the Leningrad Hospice Society. Sharon helped me by putting me on the invitation list so I should be able to make at the Consulate functions the acquaintances of her guests, Russians and visiting Americans, who might be willing to help us. Mrs Matlock suggested that I should ask you and your husband, in his capacity as Head of Cultural Section responsible for compiling the relevant invitation lists, to help me in the same way.

It was at one such function given by Lady Braithwaite at the Embassy that Zorza met Lord Gowrie, Chairman of Sotheby’s auctioneers, and discussed with him the possibility of an auction to raise money for the hospices. He explains:

We have made tentative plans to ask Russian painters to donate their work. We will also try to obtain gifts of antiques. We are hoping that the support the hospice cause enjoys in high places in Moscow will enable us to make a breakthrough in securing export licences.

Lord Gowrie responded favourably to Zorza’s overtures and offered the advice of staff with experience in the Soviet Union. In the uncertain days of 1991, it was an ambitious project. Gnezdilov comments: ‘Victor had big ideas and very big plans; there was always something exciting happening around Victor.’ In the end, it was one of Victor’s schemes in which ambition outweighed possibility and he was left disappointed.

Despite these setbacks, there were outstanding successes. Death of a daughter resonated with those who
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wanted better care for their relatives during the last weeks of life. The influential articles of Vasinsky and Krivopalov gave a much-needed Russian perspective on the benefits of hospice care. Respected figures, many of whom had withstood tyranny and oppression, anointed the movement with integrity, and the hospice societies provided a protective shield against the predatory forces of vested interests.

Moscow

From the day he returned to Russia, Zorza was convinced that Moscow was the ideal place – the only place – to open his first hospice. With a reputation gained in the capital, the hospice approach would spread easily throughout the regions. The support of leading Muscovites and endorsement by the Ministry of Health would add kudos and prepare the way for further developments. Centres of excellence would quickly be established and as homecare began to supplement the in-patient units, the beneficiaries of this country-wide movement would be the Russian people. Such was the dream.

The reality was different. There was no shortage of effort as Zorza tirelessly pursued his goal. Yet despite the advocacy, the networking, the applications and the promises, there was no closure. One year dragged into the next. As the Soviet system crumbled, government officials were constantly replaced and each new bureaucrat required a fresh submission. Weary and frustrated, Zorza writes to BSHS trustee Martyn Lewis:

We were having a very difficult time of it before the Coup [1991] because the Party bureaucrats were being obstructive in the best Communist tradition. We had originally planned to open the Moscow hospice in mid-October, and had been promised a building by then, but in the middle of the nurses’ course we were told that the accommodation would not now be available until a year after that, if at all. We were being given the run-around because some people didn’t like the idea of a hospice, while others were trying to get their hands on a project which they saw as a way to wheedle money and goods out of the West. All my three years seemed wasted, there was no way to get round the obstacles, my attempts to tackle them head on were little better than banging my head against a brick wall. The whole thing seemed to be crashing round my ears.79

These reasons, combined with Zorza’s deep-seated belief in a systemically corrupt bureaucracy, persuaded him that the answer lay in resolute perseverance and the discovery of flawless individuals who could take his ideas forward. He had a point. But tellingly, Inessa Slavutinskaya sheds a different light on the problem and suggests that the cause lay elsewhere:

The main problem was that our authorities in the Ministry of Health thought they could do everything by themselves and they didn’t need a person from England to teach them. They didn’t want to learn, you see. The second problem was that in any case the Soviet Union just didn’t have money for these patients.80

In this complex scenario, Zorza was certain that education and training were crucial if hospice care was to gain ground and become accepted. Ever the optimist, he prepared for that day by training a nucleus of doctors and nurses in palliative care. He needed help, however, and in this instance turned to the Hospice Information Service, based then at St Christopher’s. Avril Jackson recalls:
I encouraged him to apply to attend St Christopher’s 1991 *Building Bridges* International Conference and, although I’d had quite a lot of telephone exchanges with Victor, it wasn’t really until May ‘91 that I actually met him in the flesh at the conference. It was at that meeting that he stood up and encouraged people to sign up to go out to Russia and of course, as you probably know, the woman who was then Head of Nursing Education at St Christopher’s, Virginia Gumley, was I think first in line to go out and sign up and to go out to Russia.\(^{81}\)

In fact, Virginia Gumley was one of several nurse tutors who offered to teach in Russia. The training need was quickly assessed and a course in palliative nursing – *Compassion with Competence* – was planned to run in Moscow from July to September that year.\(^{82}\)

During this time, three teams of nurse tutors taught consecutively for one month each. The first team was led by Jean Roch,\(^{83}\) the second by Virginia Gumley\(^{84}\) and the third by Wendy Jones.\(^{85}\) Russian nurses travelled long distances to attend. Virginia Gumley:

> Thirty-two nurses from seven different towns attended, from Kaliningrad near the Polish border, to Omsk in Siberia. I found the nurses highly motivated, hard working and very keen to develop their skills. Many a teacher in the United Kingdom would have been delighted to have such a hard-working group.\(^{86}\)

Two problems arose, however, one practical the other political. Wendy Jones:

> One of the difficulties we had was finding patients to look after. We had a group of students drawn from seven different cities and we wanted to include some practical aspects of nursing care for those students; but first we had to find our patients because they were not gathered together in one place. And it was Jean Roch who bore the
brunt of those problems because she was the first of the three of us to take that course. And I know Jean won’t mind me telling you: one of the most incredible problems she had was where to find the patients. She approached the oncologists who discharged these people from their care and got lists of addresses and what-have-you, but the oncologists themselves never followed them up. Once they’d discharged them, having decided that they couldn’t do any more, they never knew what became of them after that. And so poor Jean would find herself standing on the doorstep or whatever, knocking at the door of a flat asking after somebody who might since have died. And you can imagine how traumatic that would have been for her and for everybody involved.  

The second, very different problem, related to the August Coup, the attempt to seize power by a group of Communist hard-liners who thought Gorbachev’s reforms had gone too far. It was a worrying time for a group of Russian and British nurses dislocated from their homes and living in Moscow. The Soviet Union was in its last days. Tanks were on the streets of the capital. Confusion was rife and the situation changed by the hour. Wendy Jones recalls the impact:

During the time that I was in charge, the August Coup took place. This called for different management of the whole group and alterations to the timetable if any significant learning was to take place. The age range of the group was very wide (ranging from about 17 years to 50 plus). Consequently, there was hardly a member who had not some sort of emotional attachment to the soldiers or militia involved, either as boyfriend, fiancé, husband, brother or political activist. With the daily and nightly activities at the barricades and on the streets of Moscow, the anxiety of the group by nine o’clock each morning was high. As an educationalist, I recognised that nothing of any value would take place until this anxiety was, at least in part, relieved. It happened that one of the interpreters was also something of a political animal and I realised I would not get much out of him until he too knew what was going on. I therefore agreed that he should go to the centre of the action each morning – but carefully! – in order to gather the most recent news. None of this was reported in the press at the time, and in fact the newspapers were not published for a day or two. He would report to the group of students between nine and 10 o’clock each day and then there was some chance of getting on with the day’s modified programme.

It was also at this time that the British Embassy was advising British nationals to leave the country. I therefore had to give my team members the opportunity, if they wished, to follow the advice given and leave Moscow. I am happy to report that neither of them did, though there was a moment when I thought they might.

Happily for Victor, when the Coup had run its course, the swing towards democracy and the elevation of supportive

Virginia Gumley: ‘I found the nurses highly motivated.’
politicians foreshadowed a change in fortune for the hospice movement. Zorza writes:

[After] the counter-coup, our friends in the democratic leadership, who had earlier tried to help us but couldn’t prevail against the bureaucrats, were now in a position to give orders. Among our supporters are Edvard Shevardnadze, Anatoly Sobchak, and the Deputy Mayor of Moscow, Luzhkov, who was elevated by the counter-coup to deputy prime minister. He intervened personally to sweep away the obstacles which the party apparatchiks had been putting in our way. Work on the building we have been given by the Moscow Soviet is now going full speed ahead; we have been promised that the conversion will be completed by the New Year [1992].

Energised by these developments, Victor embarked on a wave of activity. The Duchess of Kent was identified as a suitable person to lay the foundation stone of the Moscow Hospice. The following letter to her secretary – written one month after the Coup – gives an insight into Victor’s activity at this time:

The Leningrad hospice, which we opened last year as a pilot project, is now working at full stretch and has more than fulfilled its promise. We brought over to Russia five

Boris Yeltsin addresses a crowd from behind bulletproof shields during the August Coup, 20 August 1991.
teams of British Hospice doctors and nurse tutors to train Soviet physicians and nurses. They will form the nuclei of the Moscow hospice and of the six others we plan to start after we have opened the Moscow one. The health authorities of the six regions we chose have agreed to designate locations, provide buildings and the staff (to be picked and trained by us). We selected these regions with a view to providing focal points from which the concept and practice of hospice might radiate.

The doctor we have picked as the medical director-designate of the Moscow Hospice, a gifted young oncologist has just left this country after completing his training at Sobell House in Oxford. We have obtained a gift of Western medicines which will provide pain relief for all the patients of the Leningrad and Moscow hospices for one year, British nurse tutors will hold a second course in Moscow from mid-January to mid-March, after which we will be ready to open the Moscow hospice.90

As time passed, Zorza’s plans again became frustrated, on two fronts. First, the medical director-designate had a change of heart and decided that palliative medicine was not for him. At a stroke, the costly investment in education and training was lost and a new physician, sympathetic to the hospice ideal had to be found – urgently! Compounding this disappointment, progress with the building remained achingly slow. The time had come for decisive action or the stalled initiative would be lost.

Victor considered his options. In the end, after a painful reappraisal of the whole Moscow project, he adopted a new approach: a home care service based in the designated – yet incomplete – hospice building, coupled with the appointment of an experienced doctor who could bring leadership and stability to the service. Though running against the grain of his previous strategy, this fresh thinking was an outstanding success on both fronts. And the key to this success lay in the appointment of the new medical director.

Vera Millionshchikova was a radiotherapist who, over the years, developed an interest in caring for those abandoned by the medics. By the early 1990s she was looking towards retirement but then heard of Zorza and decided to attend his seminar on hospice care. When they met, she was captivated by his commitment, his strength of character, and the way hospice care seemed uncannily in tune with her interests and practice. She recalls:

Victor told me: ‘Although you don’t know it, what you’re doing is part of the work of a hospice.’ And that’s when I started to work with him. At this time in Moscow, it was very
difficult to organise a hospice, but by 1994 we had begun a home care service organised from two or three rooms in a government building. Then, little by little, we grabbed the lot and opened an in-patient hospice in 1997.91

In conditions that were less than ideal, the home care service made important contributions to the relief of suffering and the growing awareness of hospice during the time that the in-patient unit was being prepared. Serving a population of 350,000 in the centre of Moscow, around 500 patients had been cared for by the spring of 1997. A day hospice opened in 1995.92

It took eight years for the in-patient hospice to come into being. Unsurprisingly, feelings of excitement were tinged with relief on the day of the opening. Guests of honour included Eileen, Victor’s partner, and the indefatigable Wendy Jones. As the ceremony was performed by Naina Yeltsin – wife of the Russian President – thoughts turned to Victor and his unremitting battle to complete his task. And of the sadness that he never lived to see this day. Although Victor died during the previous year, he became aware before his death that the home care service was thriving and the premises were being adapted for hospice use. A stream of photographs,
warmly received by Victor, recorded each phase of development, and he was pleased to receive news from friends and BRHS trustees after their visits to the capital.

Though Russia’s first hospice opened in St Petersburg, Moscow always had a special place in Zorza’s heart. It was here that he made his first, enthusiastic, attempts to introduce the hospice ideal to the Russian people; and here, where he exhausted himself before turning his attention to St Petersburg. For all that, it was not in his nature to give up. Despite his acute sense of failure, his persistence was rewarded when hospice care was finally adopted by people with influence. Success in Moscow would take longer than in St Petersburg, but before he died, Victor knew that the outcome was not in doubt.

Zorza’s death was keenly felt in Moscow. To Vera Millionshchikova, and many others in Russia, he had become a friend, an ally, a mentor and a strategist – and his clarity of approach would be missed, especially in the changing times of the 1990s. For her part, Dr Millionshchikova had no intention of letting Zorza’s role become overlooked, and regularly...
conveyed his hospice vision and the story of Jane’s death to seminar and conference delegates.

Under her leadership, the hospice continued to expand. By 2001 around 80 staff at First Hospice, Moscow, cared for 200 cancer patients per month. The workforce included: five doctors; 23 nurses; 30 junior nurses; six social workers; three psychologists; a lawyer; a volunteer chaplain; and about 200 other volunteers. Millionshchikova:

We have a volunteer co-ordinator and each day we decide how many people we need to bring in. For example, on the in-patient unit they might need volunteers to help feed the patients and volunteers to help take patients outside – so there’s probably only five or six patients on the ward – but the volunteers are chosen and called in.

Significantly, Millionshchikova continued to maintain Zorza’s vision of the hospice ideal:

‘In our poor country, with such poor people, we simply can’t ask patients for money to die. Everything is free.’

Zorza would have been pleased to hear it.
Notes

2. Nikita Sergeyevich Khrushchev (1894–1971) became first secretary of the Communist Party after a power struggle following Stalin’s death in 1953, a position he held until 1964. He famously denounced Stalin at the 20th Party Congress in 1956, accusing him of mass murder. He lost credibility after the Cuban missile crisis of 1962 and was deposed by Party members in 1964, after which when Leonid Brezhnev came to power.
3. Mikhail Sergeyevich Gorbachev (b. 1931) led the Soviet Union between 1985 and 1991, when his attempts at reform brought an end to the Cold War (1945–91) but caused the collapse of the Soviet Union.
6. Boris Nikolayevich Yeltsin (b. 1931) was President of Russia from 1990 until December 1999. He is known for his rush to the White House in Moscow to defy the August Coup of 1991 and for his speech from the turret of a tank.
7. For example, the truth concerning the massacre of Polish officers during the Second World War as authorised by Stalin.
8. The 20th Party Conference was held in 1956.
21. The nomenklatura were people in positions that needed Party approval; they were the political and Party elite.
28. Victor Zorza talking to Stephen Marder, November 1994
36. ‘The defined daily dose is the assumed average maintenance dose per day … Drug consumption figures are presented as numbers of DDDs per population per day for comparative purposes in drug utilization studies. In the INCB technical publications, DDD
figures were calculated as the annual average dose of drug consumed, computed over five years, per million inhabitants in a given country.' World Health Organisation, *Achieving Balance in National Opioids Control Policy* Geneva: WHO, 2000: 30.


41. A ‘soviet’ is one of the legislative assemblies that existed at local, regional, and national levels in the former Soviet Union.

42. Inessa Slavutinskaya, IOELC interview, 24 February 2003.


44. Inessa Slavutinskaya, IOELC interview, 24 February 2003.


50. In 2002, the salaries of physicians were still around 70 per cent of the average wage in Russia.


58. Letter from Robert Twycross to Kurt Wuest, director of Mundipharma, 3 September 1990.


64. Dmitri Likhachev, an intellectual and author of more than 1,000 scholarly works, devoted his life to defending his country's Christian and cultural heritage. He resisted Stalin and survived four years (1928–32) in Soviet forced-labour camps. Likhachev was appointed to the staff of the Institute of Russian Literature in St Petersburg and eventually became a member of the Duma.

65. Andrei Dmitrievich Sakharov (1921–89). Born in Moscow, Andrei Sakharov studied physics at the University of Moscow and became associated with the development of the Soviet hydrogen bomb. He later became critical of Soviet totalitarianism and a strong advocate of human rights, winning the Nobel Peace Prize in 1975. When he opposed the Soviet intervention in Afghanistan (1979), he was exiled in Gorky without trial (1980). In 1986, Gorbachev brought him back to Moscow where he supported the move towards democracy.


67. Anatoly Alexandrovich Sobchak (1937–2000) was a St Petersburg lawyer who played an important role in the collapse of Communism in Russia. A leading statesman, he represented the city in the Supreme Council of the Soviet Union and was a friend of Boris Yeltsin, the first President of independent Russia.

68. From the proposed constitution of the American Soviet Hospice Society, July 3 1991.


73. Letter from Victor Zorza to Lord Gowrie, 28 November 1990.


75. Andrei Gnezdilov, IOELC interview, 2, 4 April 2003.

76. Stephen Connor, IOELC interview, 1 April 2002.


78. Andrei Gnezdilov, IOELC interview 2, 4 April 2003.


81. Avril Jackson, IOELC interview, 1 September 2002.

82. Training courses were held during the 1990s at various venues in Russia, including Ivanovo, Tula, Kemerovo and Yaroslavl. See:

83. Jean Roch worked at St Luke’s Hospice, Sheffield.

84. At this time Virginia Gumley worked at St Christopher’s Hospice; she was later to work for the charity Health Prom.

85. Wendy Jones was working at St Francis Hospice, Romford; she later became director of the British Russian Hospice Society.


87. Wendy Jones, personal communication, 7 May 2003.


