Patient Information

Patient information and consent to treatment of trigeminal neuralgia by percutaneous (radiofrequency or glycerol) lesioning

Key messages for patients

- **Please read your admission letter carefully.** It is important to follow the instructions we give you about not eating or drinking or we may have to postpone or cancel your operation. You will need to be nil by mouth from midnight on the day of surgery.

- **Please read this information carefully,** you and your health professional will sign it to document your consent.

- **It is important that you bring the consent form with you when you are admitted for surgery.** You will have an opportunity to ask any questions from the surgeon or anaesthetist when you are admitted. You may sign the consent form either before you come or when you are admitted.

- **Please bring with you any medications you use (including patches, creams and herbal remedies)** and any information that you have been given relevant to your care in hospital, such as x rays or test results.

- Take your medications as normal on the day of the procedure **unless** you have been specifically told not to take a drug or drugs before or on the day by a member of your medical team. **Do not** take any medications used to treat diabetes.

- **Please call the clinical nurse practitioner on telephone number 01223 216189** if you have any questions or concerns about this procedure or your appointment.

After the procedure we will file the consent form in your medical notes and you may take this information leaflet home with you.

**Important things you need to know**

Patient choice is an important part of your care. You have the right to change your mind at any time, even after you have given consent and the procedure has started (as long as it is safe and practical to do so). If you are having an anaesthetic you will have the opportunity to discuss this with the anaesthetist, unless the urgency of your treatment prevents this.

We will also only carry out the procedure on your consent form unless, in the opinion of the responsible health professional, a further procedure is needed in order to save your life or prevent serious harm to your health. However, there may be procedures you do not wish us to carry out and these can be recorded on the consent form. We are unable to guarantee that a particular person will perform the procedure. However the person undertaking the procedure will have the relevant experience.

All information we hold about you is stored according to the Data Protection Act 1998.

Trigeminal neuralgia by percutaneous lesioning, CF087, V2, October 2013
About treatment of trigeminal neuralgia with percutaneous (radiofrequency or glycerol) lesioning (percutaneous rhizotomy)

Trigeminal Neuralgia (TN) is a very severe one-sided facial pain which, typically, is shooting, stabbing, or electric shock-like in nature. Each spasm may last only for a few seconds, but often there will be multiple episodes which follow in quick succession. Symptoms usually fluctuate in severity, and there may be weeks or many months between bouts. The pain is often triggered by things such as eating, drinking, talking, touching the face or even cold wind.

The trigeminal nerve (the nerve of feeling to the face) has three branches:

- The upper division (ophthalmic) supplies the skin of the upper eye lid and forehead.
- The middle division (maxillary) supplies the cheek, the lower eye lid, upper jaw/teeth, and the side of the nose.
- The lower division (mandibular) supplies the lower jaw, lower teeth and lower lip.

There are several surgical treatment options for this condition. Surgery is indicated if pain relief is either inadequate with medication (the commonly used drugs are carbamazepine, gabapentin, pregabalin and amitriptyline) or the side-effects are intolerable. Your surgeon will already have explained to you the various treatment options (microvascular decompression, percutaneous lesioning or gamma-knife radiosurgery) and reached a decision jointly with you on the one most suitable in your case.

The aim of the procedure is to give pain relief by partially deadening the divisions(s) of the nerve in which the pain arises. Usually, but not invariably, this will result in at least some facial numbness. This may be temporary or permanent. The procedure goes by a variety of names because it can be done in several different ways (i.e. using either heat, a chemical or mechanical compression to damage the pain fibres within the nerve).

Intended benefits

The aim of this procedure is to relieve facial pain.

Who will perform my procedure?

This procedure will be performed by a neurosurgeon.

Before your procedure

Most patients attend a pre-admission clinic, at this clinic, we will ask for details of your medical history and carry out any necessary clinical examinations and investigations. Please ask us any questions about the procedure, and feel free to...
discuss any concerns you might have at any time.

We will ask if you take any tablets or use any other types of medication either prescribed by a doctor or bought over the counter in a pharmacy. Please bring any packaging with you.

**It is very important to let the surgical team know if you have been fitted with an implanted electrical device such as a pacemaker or cochlear implant**

This procedure involves the use of general anaesthesia. We explain about the different types of anaesthesia or sedation we may use at the end of this leaflet. You will see an anaesthetist before your procedure.

Most people who have this type of procedure will be able to go home either the same day or the following day. Your doctor will discuss the length of stay with you.

You will need to be nil by mouth from midnight on the day of surgery.

**Hair removal before an operation**

There is no need for any hair removal for this procedure, even if you have a beard.

**During the procedure**

- The procedure is performed under general anaesthetic. A needle is passed through the skin of the cheek near the angle of the mouth and directed, under x-ray control, into the trigeminal nerve inside the skull.

- The procedure is performed in one of two ways. Radiofrequency lesioning uses heat to reduce the sensitivity of the nerve. The alternative is to inject a chemical (glycerol) around the nerve. There are advantages and disadvantages to each and these will be discussed with you before the procedure. Radiofrequency lesioning cannot be used in people who are fitted with pacemakers and, in general, it is not suitable for people who have pain in the ophthalmic (see above) division of the nerve. In either of these instances, glycerol will be used instead.

**Radiofrequency lesioning**

- The term radiofrequency refers to a heating current which is used to destroy, in particular, the pain fibres within the nerve under general anaesthetic. Once the needle is in place, anaesthesia is lightened and a small electrical current is passed through the needle. This causes tingling in the face and is used to establish that the correct area of the nerve has been identified. Once this has been confirmed you will be anaesthetised again and a radiofrequency current is passed through the needle to desensitise that part of the nerve.

- Although you will be awake briefly to test that the needle is in the correct position, you will remain lightly sedated and most patients have no memory of
being woken up. The procedure usually takes about 15 minutes, followed by a short spell in recovery.

**Glycerol Rhizotomy**

- As with radiofrequency lesioning, a needle is passed up through the cheek into an opening in the base of the skull. With this procedure it is not necessary for the patient to be woken up. However, once the glycerol has been instilled it will be necessary for you to sit up with your head forwards for about half an hour. Your face may feel a burning sensation for a time followed by a variable degree of numbness.

**After the procedure**

Once your surgery is completed you will usually be transferred to the recovery ward where you will be looked after by specially trained nurses, under the direction of your anaesthetist. The nurses will monitor you closely until the effects of any general anaesthetic have adequately worn off and you are conscious. They will monitor your heart rate, blood pressure and oxygen levels too. You may be given oxygen via a facemask, fluids via your drip and appropriate pain relief until you are comfortable enough to return to your ward.

After certain major operations you may be transferred to the intensive care unit (ICU/ITU), high dependency unit (HDU), intermediate dependency area (IDA) or fast track/overnight intensive recovery (OIR). These are areas where you will be monitored much more closely because of the nature of your operation or because of certain pre-existing health problems that you may have. If your surgeon or anaesthetist believes you should go to one of these areas after your operation, they will tell you and explain to you what you should expect.

**If there is not a bed in the necessary unit on the day of your operation, your operation may be postponed as it is important that you have the correct level of care after major surgery.**

- **Eating and drinking.** After this procedure, you should be able to eat and drink within a few hours.

- **Getting about after the procedure.** We will help you to become mobile as soon as possible after the procedure. This helps improve your recovery and reduces the risk of certain complications. If you have any mobility problems, we can arrange nursing or physiotherapy help.

- **Leaving hospital.** Generally most people who have had this operation will be able to leave hospital either the same day or the following day. However, the actual time that you stay in hospital will depend on your general health, how quickly you are recovering from the procedure and your doctor’s opinion.
Resuming normal activities including work. Usually you can resume normal activities the next day. You might need to wait a little longer before resuming more vigorous activity. When you will be ready to return to work will depend on your usual health, how fast you recover and what type of work you do. Please ask your doctor for his/her opinion.

Special measures after the procedure: On discharge we recommend that you stay on your normal pain relief medication for two weeks following the procedure and then start to reduce it very gradually. We usually suggest that you reduce the medication by one tablet per week while you are pain free. However, if at any point the pain should recur then you should revert to the previous dose and continue with this regimen until you are once again pain free.

You may feel numb inside your cheek. You will be given more detailed information about any special measures you need to take after the procedure. You will also be given information about things to watch out for that might be early signs of problems (eg infection).

Check-ups and results: As a rule we do not make you a routine follow up appointment to return to the clinic after the procedure but you will be given the team's contact numbers prior to discharge should any problem arise once you are at home.

Significant, unavoidable or frequently occurring risks of this procedure

Risks of percutaneous rhizotomy

- Although numbness is not inevitable following a treatment, it is very likely that you will have at least some numbness in your face and inside your mouth (involving particularly the inside of your cheek and the side of your tongue). This may be permanent. Following radiofrequency lesioning, this numbness is usually confined to the divisions of the nerve that were affected with pain beforehand. However, occasionally it can involve the whole of that side of the face. The numbness that follows glycerol injection usually involves the whole of the affected side of the face but is less pronounced than with radiofrequency lesioning. Numbness does not cause your face to look any different from the outside but if your lips are numb you may have difficulty moving them properly at first (similar to the effect of a dental anaesthetic). If numbness affects the surface of the eye then you may not be aware if grit or dirt has blown into it and, therefore, it is necessary to take particular care to protect the eye and to seek advice if it becomes red and inflamed. Another problem with numbness is that, if the inside of the cheek is affected, it may be bitten inadvertently.

- Occasionally (2-4% of procedures) numbness can be of an unpleasant burning character. This is known as anaesthesia dolorosa. Unfortunately, this is very difficult to treat if it does occur, and is usually permanent. However, it may respond to antidepressants.
- As well as being the nerve of feeling to the face, the trigeminal nerve also controls the tension in the ear drum. The procedure therefore has a small risk of reducing hearing on the side of treatment.

- Like any other procedure, there is a small risk of infection. Because the trigeminal nerve is surrounded by spinal fluid, there is around a 1/100 risk of meningitis. Usually this responds readily to antibiotics.

- Also close to the trigeminal nerve are the nerves which make the eyes work as a pair. Were one of these to be affected then this could give rise to double vision. The risk of this is again around 1/100.

- The procedure is not always effective in relieving pain. The short term success rate is around 9/10, meaning there is around a 1/10 chance that you could go through the procedure and not be free of pain afterwards. Because, in time, the nerve is likely to re-grow, unfortunately this procedure does not usually provide permanent pain relief. At times the pain will recur within a matter of weeks or months but, more usually, pain relief will last for several years.

- The risks of serious complications (death or serious permanent neurodisability) are very small indeed. This is related to the risk of anaesthesia, in general, or damage to the carotid artery which lies close to the trigeminal nerve. The risk of serious neurodisability (stroke) is around 1/1000.

- The needle is passed up through the flesh of the cheek. This area has a rich blood supply and bruising/swelling to the cheek may occur for a few days afterwards. Because the needle passes through the chewing muscle, you may find that your jaw feels bruised and swollen for the first few days.

**Alternative procedures that are available**

The purpose of surgery is to improve quality of life. The alternatives are to continue with medication or to consider alternative surgical procedures (microvascular decompression or gamma knife radiosurgery). The surgical team will be pleased to discuss these with you.

**Information and support**

- You might be given some additional patient information before or after the procedure, for example: leaflets that explain what to do after the procedure and what problems to look out for. If you have any questions or anxieties, please feel free to ask a member of staff including doctor or clinical nurse practitioner.

- You can contact the clinical nurse practitioner via main switchboard or via the neurosurgical secretary.

- Trigeminal neuralgia association UK: [www.tna.org.uk](http://www.tna.org.uk); Telephone 01883 370214.
Anaesthesia

Anaesthesia means ‘loss of sensation’. There are three types of anaesthesia: general, regional and local. **The type of anaesthesia chosen by your anaesthetist depends on the nature of your surgery as well as your health and fitness.** Sometimes different types of anaesthesia are used together.

**Before your operation**

Before your operation you will meet an anaesthetist who will discuss with you the most appropriate type of anaesthetic for your operation, and pain relief after your surgery. To inform this decision, he/she will need to know about:

- your general health, including previous and current health problems
- whether you or anyone in your family has had problems with anaesthetics
- any medicines or drugs you use
- whether you smoke
- whether you have had any abnormal reactions to any drugs or have any other allergies
- your teeth, whether you wear dentures, or have caps or crowns.

Your anaesthetist may need to listen to your heart and lungs, ask you to open your mouth and move your neck and will review your test results.

**Pre-medication**

You may be prescribed a ‘premed’ prior to your operation. This is a drug or combination of drugs which may be used to make you sleepy and relaxed before surgery, provide pain relief, reduce the risk of you being sick, or have effects specific for the procedure that you are going to have or for any medical conditions that you may have. Not all patients will be given a premed or will require one and the anaesthetist will often use drugs in the operating theatre to produce the same effects.

**Moving to the operating room or theatre**

You will usually change into a gown before your operation and we will take you to the operating suite. When you arrive in the theatre or anaesthetic room and **before starting your anaesthesia, the medical team will perform a check of your name, personal details and confirm the operation you are expecting.**

Once that is complete, monitoring devices may be attached to you, such as a blood pressure cuff, heart monitor (ECG) and a monitor to check your oxygen levels (a pulse oximeter). An intravenous line (drip) may be inserted. If a regional anaesthetic is going to be performed, this may be performed at this stage. If you are to have a general anaesthetic, you may be asked to breathe oxygen through a face mask.
**General anaesthesia**

During general anaesthesia you are put into a state of unconsciousness and you will be unaware of anything during the time of your operation. Your anaesthetist achieves this by giving you a combination of drugs.

While you are unconscious and unaware your anaesthetist remains with you at all times. He or she monitors your condition and administers the right amount of anaesthetic drugs to maintain you at the correct level of unconsciousness for the period of the surgery. Your anaesthetist will be monitoring such factors as heart rate, blood pressure, heart rhythm, body temperature and breathing. He or she will also constantly watch your need for fluid or blood replacement.

**Regional anaesthesia**

Regional anaesthesia includes epidurals, spinals, caudals or local anaesthetic blocks of the nerves to the limbs or other areas of the body. Local anaesthetic is injected near to nerves, numbing the relevant area and possibly making the affected part of the body difficult or impossible to move for a period of time. Regional anaesthesia may be performed as the sole anaesthetic for your operation, with or without sedation, or with a general anaesthetic. Regional anaesthesia may also be used to provide pain relief after your surgery for hours or even days. Your anaesthetist will discuss the procedure, benefits and risks with you and, if you are to have a general anaesthetic as well, whether the regional anaesthesia will be performed before you are given the general anaesthetic.

**Local anaesthesia**

In local anaesthesia the local anaesthetic drug is injected into the skin and tissues at the site of the operation. The area of numbness will be restricted. Some sensation of pressure may be present, but there should be no pain. Local anaesthesia is used for minor operations such as stitching a cut, but may also be injected around the surgical site to help with pain relief. Usually a local anaesthetic will be given by the doctor doing the operation.

**Sedation**

Sedation is the use of small amounts of anaesthetic or similar drugs to produce a ‘sleepy-like’ state. Sedation may be used as well as a local or regional anaesthetic. The anaesthesia prevents you from feeling pain and the sedation makes you drowsy. Sedation also makes you physically and mentally relaxed during an investigation or procedure which may be unpleasant or painful (such as an endoscopy) but where your co-operation is needed. You may remember a little about what happened but often you will remember nothing. Sedation may be used by other professionals as well as anaesthetists.
What will I feel like afterwards?

How you will feel will depend on the type of anaesthetic and operation you have had, how much pain relieving medicine you need and your general health.

Most people will feel fine after their operation. Some people may feel dizzy, sick or have general aches and pains. Others may experience some blurred vision, drowsiness, a sore throat, headache or breathing difficulties.

You may have fewer of these effects after local or regional anaesthesia although when the effects of the anaesthesia wear off you may need pain relieving medicines.

What are the risks of anaesthesia?

In modern anaesthesia, serious problems are uncommon. Risks cannot be removed completely, but modern equipment, training and drugs have made it a much safer procedure in recent years. The risk to you as an individual will depend on whether you have any other illness, personal factors (such as smoking or being overweight) or surgery which is complicated, long or performed in an emergency.

Very common (1 in 10 people) and common side effects (1 in 100 people)

Feeling sick and vomiting after surgery
Sore throat
Dizziness, blurred vision
Headache
Bladder problems
Damage to lips or tongue (usually minor)
Itching
Aches, pains and backache
Pain during injection of drugs
Bruising and soreness
Confusion or memory loss

Uncommon side effects and complications (1 in 1000 people)

Chest infection
Muscle pains
Slow breathing (depressed respiration)
Damage to teeth
An existing medical condition getting worse
Awareness (becoming conscious during your operation)

Rare (1 in 10,000 people) and very rare (1 in 100,000 people) complications

Damage to the eyes
Heart attack or stroke
Serious allergy to drugs
Nerve damage
Death

Trigeminal neuralgia by percutaneous lesioning, CF087, V2, October 2013
Equipment failure

Deaths caused by anaesthesia are very rare. There are probably about five deaths for every million anaesthetics in the UK.

For more information about anaesthesia, please visit the Royal College of Anaesthetists’ website: www.rcoa.ac.uk
Information about important questions on the consent form

1 Creutzfeldt Jakob Disease ('CJD')

We must take special measures with hospital instruments if there is a possibility you have been at risk of CJD or variant CJD disease. We therefore ask all patients undergoing any surgical procedure if they have been told that they are at increased risk of either of these forms of CJD. This helps prevent the spread of CJD to the wider public. A positive answer will not stop your procedure taking place, but enables us to plan your operation to minimise any risk of transmission to other patients.

2 Photography, Audio or Visual Recordings

As a leading teaching hospital we take great pride in our research and staff training. We ask for your permission to use images and recordings for your diagnosis and treatment, they will form part of your medical record. We also ask for your permission to use these images for audit and in training medical and other healthcare staff and UK medical students; you do not have to agree and if you prefer not to, this will not affect the care and treatment we provide. We will ask for your separate written permission to use any images or recordings in publications or research.

3 Students in training

Training doctors and other health professionals is essential to the NHS. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a registered professional. You may, however, prefer not to take part in the formal training of medical and other students without this affecting your care and treatment.

4 Use of Tissue

As a leading bio-medical research centre and teaching hospital, we may be able to use tissue not needed for your treatment or diagnosis to carry out research, for quality control or to train medical staff for the future. Any such research, or storage or disposal of tissue, will be carried out in accordance with ethical, legal and professional standards. In order to carry out such research we need your consent. Any research will only be carried out if it has received ethical approval from a Research Ethics Committee. You do not have to agree and if you prefer not to, this will not in any way affect the care and treatment we provide. The leaflet 'Donating tissue or cells for research' gives more detailed information. Please ask for a copy.

If you wish to withdraw your consent on the use of tissue (including blood) for research, please contact our Patient Advice and Liaison Service (PALS), on 01223 216756.
Privacy & dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.

We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

Help with this leaflet

If you would like this information in large print, another language or in audio format, please ask the department to contact Patient Information on 01223 216032 or patient.information@addenbrookes.nhs.uk

Document history

Authors: Neurosurgery team
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Contact number: 01223 245151
Publish/Review date: October 2013 / October 2016
File name: CF087_trigeminal_neuralgia_v2.doc
Version number/Ref: 2 / CF087
Consent Form

Patient agreement to investigation or treatment for neurosurgery, spinal surgery or vitreoretinal surgery

Please use ‘Procedure completed’ stamp below on completion:

Interpreter's statement (if appropriate)

I have interpreted the information to the best of my ability, and in a way in which I believe the patient can understand:

Signed (Interpreter): ............................... Date: …..P/M/Y

Name (PRINT): .................................................................

Or, please note the language line reference ID number: .................................................................

Patient safety – at the heart of all we do

Addenbrooke’s Hospital | Rosie Hospital

CF087 Version 2 October 2013
Treatment of Trigeminal Neuralgia with percutaneous lesioning

The aim of this procedure is to relieve / reduce facial pain.

Failure/recurrence, facial numbness/burning facial pain, infection (meningitis), bleeding, double vision/ hearing loss, eye numbness. 1 in 1,000 risk of stroke

c) what the treatment or procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient:

d) any extra procedures that might become necessary during the procedure such as:

   □ Blood transfusion  □ Other procedure (please state)

   e) Was the patient born after 1 January 1997?  □ Yes  □ No

The following information leaflet has been provided:

CF087 Treatment of trigeminal neuralgia with percutaneous lesioning; version 2; October 2013

or  □ I have offered the patient information about the procedure but this has been declined.

This procedure will involve:

□ General and/or regional anaesthesia  □ Local anaesthesia  □ Sedation  □ None

Signed (Health professional): ___________________________  Date: __________/________/________

Name (PRINT): _______________________________________  Time (24hr): _______ : _______

Designation: _________________________________________  Contact/bleep no: ____________________
C  Consent of patient/person with parental responsibility

I confirm that the risks, benefits and alternatives of this procedure have been discussed with me and that my questions have been answered to my satisfaction and understanding.

Important: please read the patient information on ‘Consent’ and then put a tick in the relevant boxes for the following questions:

1  Creutzfeldt Jakob disease (CJD)
   a) Have you ever been notified that you are at risk of CJD or variant CJD for public health purposes? If yes, please inform your health professional.
      □ Yes □ No

   b) Have you had a history of CJD or other prion disease in your family?
      □ Yes □ No

   c) Have you ever received growth hormone or gonadotrophin treatment?
      If yes, please give details below:
      Please specify:
      (i) whether the hormone was derived from human pituitary glands
      □ Yes □ No

      (ii) the year of treatment

      (iii) whether the treatment was received in the UK or another country
      □ UK □ Other

   d) Have you ever had surgery on your brain, eye or spinal cord?
      If yes, please give details below:

   e) Since 1980, have you had any transfusions of blood or blood components (red cells, plasma, cryoprecipitate or platelets)?
      If yes, please answer questions below:
      Have you either:
      (i) received more than 50 units of blood or blood components,
      □ Yes □ No

      or

      (ii) received blood or blood components on more than 20 occasions
      □ Yes □ No

      Where possible, please provide the names of all the hospitals where you received blood or blood components:

In the case of a positive reply to any CJD question, staff should immediately inform Infection Control on ext 3497 (bleep numbers 152-198 or 151-803) and the theatre co-ordinator (24 hour bleep number 152-585); out of hours contact the on call medical microbiologist via the hospital contact centre.

2  Photography, Audio or Visual Recording
   a) I agree to the use of any of the above type of recordings for the purpose of diagnosis and treatment.
      □ Yes □ No

   b) I agree to unidentified versions of any of the above recordings being used for audit and medical teaching in a healthcare setting.
      □ Yes □ No

3  Medical Training
   I agree to the involvement of medical and other students as part of their formal training.
      □ Yes □ No
Use of Tissue

a) I agree that tissue (including blood) not needed for my own diagnosis or treatment can be used and stored for ethically approved research which may include ethically approved genetic research. □ Yes □ No

b) Where additional clinical information is needed for the purposes of ethically approved research, I agree that relevant sections of my medical record may be looked at by researchers or by relevant regulatory authorities. I give permission for these individuals to have access to my records. □ Yes □ No

I have listed below any procedures that I do not wish to be carried out without further discussion.

I have read and understood the Patient Information entitled Consent and the above additional information. I agree to the procedure or treatment.

Signed (Patient): __________________________ Date: ____________

Name of patient (PRINT): __________________________

If signing for a child or young person; delete if not applicable.
I confirm I am a person with parental responsibility for the patient named on this form.

Signed: __________________________ Date: ____________

Relationship to patient: __________________________

If the patient is unable to sign but has indicated his/her consent, a witness should sign below.

Signed (Witness): __________________________ Date: ____________

Name of witness (PRINT): __________________________

Address: __________________________

D Confirmation of consent

Confirmation of consent (where the treatment/procedure has been discussed in advance)

On behalf of the team treating the patient, I have confirmed with the patient that she/he has no further questions and wishes the treatment/procedure to go ahead.

Signed (Health professional): __________________________ Date: ____________

Name (PRINT): __________________________ Job title: __________________________

Please initial to confirm all sections have been completed:

E Withdrawal of patient consent

□ The patient has withdrawn consent (ask patient to sign and date here)

Signed (Patient): __________________________ Date: ____________

Signed (Health professional): __________________________ Date: ____________

Name (PRINT): __________________________ Job title: __________________________